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On behalf of
13 Pregnancy, Baby and Parent Organisations [‘PBPO’]
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THE COVID-19 PANDEMIC

WITNESS STATEMENT OF JENNY WARD ON BEHALF OF 13 PREGNANCY, BABY AND PARENT ORGANISATIONS

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I. INTRODUCTION AND BACKGROUND TO THE 13 PBPOs

A. Introduction

1. My name is Jenny Ward and I am the Chief Executive of The Lullaby Trust. I am also Chair of the Pregnancy and Baby Charities Network **('the Network'**). I provide this statement on behalf of 13 Pregnancy, Baby and Parent Organisations ('**PBPOs'**), which collectively have been granted Core Participant status in Module 3 of the Covid-19 Public Inquiry ('**the Inquiry'**).

2. This statement responds to the Inquiry's request dated 13 March 2023 under Rule 9 of the Inquiry Rules 2006 ('**Rule 9 Request'**). The Inquiry proposed in the Rule 9 Request that one individual provide the statement on behalf of the PBPOs. As Chair of the Network, the PBPOs consider that I am best placed to be that individual. I should also state, however, that whilst all 13 PBPOs are members of the Network, not all members of the Network are represented within the PBPOs. I am therefore not giving this statement on behalf of the Network, but on behalf of the 13 PBPOs which have Core Participant status.

3. I make this statement from facts that are within my own knowledge and belief, except where otherwise stated. Where evidence relates to or has been provided by a particular organisation, I have made that clear. Where the PBPOs collectively express a view, I have indicated that is the case. Where facts are not within my own knowledge or belief, I have stated the source of that knowledge and confirm they are true to the best of my knowledge and belief, relying on the material provided by individual organisations and in reliance of their internal due diligence procedures.

4. 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) The Pelvic Partnership, (11) Pregnancy Sickness Support, (12) Tommy's and (13), Twins Trust.

5. A number of PBPOs have obtained survey responses for the purpose of responding to the Rule 9 Request, or for their own purposes before, to give personal context to the issues raised. Throughout this statement some quotations have been included taken from those surveys, as well as service users and other people connected to the PBPOs. These appear in blue boxes labelled Q1 – Q74.

B. Each of the PBPOs

Aching Arms

6. Aching Arms has, since August 2013, operated as a small registered charity set up as a Charitable Incorporated Organisation (**'CIO'**) registered with the Charity Commission in England and Wales to provide support to people (parents, their families and friends) who have experienced baby loss (when a baby dies in utero, at birth, or soon after birth). It also provides education on experiences of baby loss (including particularly to healthcare professionals) and supports and promotes research into baby loss.

7. Due to the formation of the CIO, Aching Arms does not have formal membership but instead consists of an estimated 140 volunteers including our Trustees and a Trustee board.

8. The charity works in the same way across all four nations of the UK. The wide network of Aching Arms volunteers prepare and deliver the charity's signature 'comfort bears' to hospitals in England, Wales, Scotland and Northern Ireland. Aching Arms has a greater presence in England, as there are more hospitals with maternity care there, but have a presence in a good number of hospitals in the other three nations, offering their comfort bears to parents in their care. In Northern Ireland, Aching Arms works with every NHS Trust. Last year, Aching Arms donated 4,277 bears to hospitals and posted 1,921 bears directly to parents who contacted the charity. The charity's free health professional awareness training is either available in person, online or via their training film and is accessed by health professionals in all four nations of the UK. The charity's support services for parents and their families are accessed by telephone, text or email making them available to families across the UK.

Baby Lifeline

9. Baby Lifeline is a national charity established in 1981 that supports frontline NHS staff to prevent injuries and deaths in and around childbirth. Its aim is to improve safety in maternity for mothers, birthing people, babies, and frontline maternity professionals. It does this by providing training related to avoidable harm, by purchasing and developing much-needed equipment, and by conducting relevant research.

10. The charity is a conduit between frontline professionals; representatives from healthcare, patient safety, and law (via their own Multi-Professional Advisory Panel); and families (via their Family Voices Group). Baby Lifeline is not a membership-based organisation. Baby Lifeline works with all four nations in the UK in each area of their work but find that they have most engagement in England.

Bliss

11. Bliss was founded in 1979 by a group of concerned parents who discovered that no hospital had all the equipment or the trained staff it needed to safely care for premature and sick babies.

Bliss has grown into the leading UK charity for the 90,000 babies born needing neonatal care every year. Bliss is not a membership-based organisation.

12. Bliss exists to give every baby born premature or sick in the UK the best chance of survival and quality of life. Bliss champions their right to receive the best care by supporting families, campaigning for change, supporting professionals, and enabling life-changing research. Bliss works with all 191 neonatal units across the UK, which are sub-divided into special care baby units (SCBUs), local neonatal units (LNUs), and neonatal intensive care units (NICUs), which provide a progressively more intensive level of care for babies born premature or sick.

13. Bliss operates across all four nations of the UK, and since 2009, has also been registered with the Scottish Charity Regulator as Bliss Scotland. Bliss Scotland is part of Bliss and works to achieve the same vision and mission for every baby born needing neonatal care in Scotland.

The Ectopic Pregnancy Trust

14. The Ectopic Pregnancy Trust ('The **EPT'**) is a charity based in the UK specialising in ectopic pregnancy.[1] It was established in 1998, founded in memory of Sophie Winter by her parents. Sophie lost her life to a misdiagnosed ectopic pregnancy. The charity strives to raise awareness of the condition among the public and healthcare professionals so that symptoms can be quickly identified and women and pregnant people can get the care that they need fast and provides information to those diagnosed with ectopic pregnancy.

15. The EPT provides information and support to anyone affected by ectopic pregnancy across England, Wales, Scotland and Northern Ireland, with the majority of activities being within England. Its support services are offered through email exchanges, phone calls, Zoom group sessions, and online message boards and its website covers comprehensive medically evidenced information dedicated to ectopic pregnancy. The EPT disseminates its patient information pack to hospitals across the UK. Virtually all early pregnancy units distribute the charity's information to patients and/or signpost to its services. The EPT is not a membership-based organisation.

Group B Strep Support

16. Group B Strep Support is a registered charity which was founded in 1996 by Jane and Robert Plumb six months after their baby Theo died, aged 17 and a half hours, from group B Strep ('**GBS'**) infection. Group B Strep Support is the UK's leading source of support for families and health professionals affected by GBS. The charity uses evidence-led information to educate the public, doctors and midwives about GBS and provides information to affected families. It

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[1] Given this, The EPT have throughout included "early pregnancy services" in the term "maternity services" when providing information, as that is the relevant term for ectopic pregnancy care.

also undertakes campaigning to improve GBS identification, prevention and treatment and supports research into GBS.

17. Group B Strep Support is not a membership organisation. As a registered charity it has a Board of Trustees who are legally responsible for their activities, alongside a volunteer expert Medical Advisory Panel and Parent Advisory Panel. Group B Strep Support are also incorporated as a registered limited company. The charity operates across all four nations of the UK.

ICP Support

18. ICP Support was established in 1991 and is the only UK-based charity that supports women and birthing people suffering with intrahepatic cholestasis of pregnancy ('**ICP'**), a complex liver condition of pregnancy caused by a combination of hormones, genetics and environment. It is the most common pregnancy specific liver condition, affecting around 5,500 women and birthing people a year in the UK, and is associated with premature labour, fetal distress and, in the worst cases, stillbirth.

19. The charity provides up to date information and advice on ICP which significantly improves the quality of life of around 7,500 people affected by ICP each year (both UK and non-UK based). It does this through its online support platforms and telephone support. It also raises awareness and promotes and funds research into ICP. The charity's vision is that every ICP baby is born safely. ICP supports just over 12,000 people in their support groups, some of whom will not be pregnant. ICP also support people who do not join the groups on social media but who instead use their support services via email and telephone. ICP supports people from all over the four nations on the UK as well as internationally.

The Lullaby Trust

20. The Lullaby Trust was originally formed as The Foundation for the Study of Infant Deaths. Following the death of baby Martin Charles de Selincourt on 30 May 1969, the organisation was founded by Martin's grandmother Nancy Hunter-Gray. The Lullaby Trust aims to reduce the number of babies dying from sudden infant death syndrome ('**SIDS'**). It does this by educating parents on how they can reduce the risk of SIDS and investing over £12 million in research. The Lullaby Trust also supports bereaved families through its helpline and befriending scheme. The Lullaby Trust operates throughout England, Wales and Northern Ireland.

21. The Lullaby Trust is a company and registered charity. As such, it has a Board of Trustees and 72 formal 'members' of the company. Amongst other functions, in the last reporting year it provided 885 bereaved family members with support, assisted 2,566 families with information on safer sleep and received 1,272 bookings from professionals for training on safer sleep advice.

The Miscarriage Association

22. The Miscarriage Association is a charity registered in England and Wales, founded in 1982, serving people across England, Scotland, Wales and Northern Ireland. It offers support and information to anyone affected by miscarriage, ectopic pregnancy or molar pregnancy. It does this via its staffed helpline, live chat service, a suite of detailed patient information leaflets; peer support groups (both online and in person), email, a private forum and social media. The Miscarriage Association works to maintain and improve care for people affected by pregnancy loss by working with and offering training to healthcare professionals and supplying them with patient information leaflets. The Miscarriage Association also encourages better support in the workplace through its employer support, consultancy and training service; and it supports and participates in clinical and qualitative research around pregnancy loss.

23. The Miscarriage Association provides direct support to approximately 10,000 people per year. It has a small formal membership of 129 individuals in accordance with its Articles of Association as a charitable company.

National Childbirth Trust

24. National Childbirth Trust ('**NCT**') is the charity that supports people as they become parents. Founded in 1956, NCT is the UK's largest and best-known charity for all parents. Every year it supports 100,000 parents through antenatal education classes and infant feeding support. Across the UK and the Channel Islands, NCT brings together many thousands more through its postnatal programmes and volunteer-led community events.

25. NCT is a grassroots community of volunteers, practitioners, members, students, staff and campaigners, all committed to responding to the challenges facing new and expectant parents today. NCT is a membership organisation and in its 2021 annual report it recorded 29,202 members.

The Pelvic Partnership

26. The Pelvic Partnership is a small national charity, with around 200 members, offering support and information to women and birthing people experiencing pregnancy-related pelvic girdle pain ('**PGP**').

27. The Pelvic Partnership was founded in 2002 by a small group of women with PGP coming together to support others experiencing the condition. The same ethos continues today, as the charity raises awareness about PGP and how it can be safely and effectively treated.

28. The Pelvic Partnership gives women and birthing people the tools and confidence to access NHS and private treatment for their PGP through the charity's website, free e-book and other

downloadable resources and its social media channels. It also supports women and birthing people on the path to recovery through its volunteer helpline, Facebook support group and by providing 1:1 online support.

29. The Pelvic Partnership has over 3,300 service users in their Facebook support group and 8,000 on Instagram. All their resources and information are available for free to ensure that women and birthing people can get the support and information they need. The charity offers support and information to women and pregnant people across the four nations of the UK. As the charity was founded in Oxfordshire, historically most of their activity has taken place in England but they have a growing presence in Scotland due to the hard work of Trustees north of the border.

Pregnancy Sickness Support

30. Pregnancy Sickness Support was founded in 2002 and is the only registered UK charity working to improve care, treatment and support for women and birthing people suffering from nausea and vomiting in pregnancy and the severe form of the condition, hyperemesis gravidarum ('**HG**'). It provides a free helpline to give information and support, offers high quality peer support to those suffering, produces information to inform and educate doctors and healthcare professionals about pregnancy sickness as well as aiming to raise awareness amongst the public.

31. Pregnancy Sickness Support is involved in ongoing research into the cause and treatment of nausea and vomiting in pregnancy and HG and the psychological impact for sufferers and their families. It in particular seeks to promote the patient voice within that research. Pregnancy Sickness Support do not have a membership model. Pregnancy Sickness Support is the only UK charity supporting all women and birthing people with Hyperemesis and supports people from all UK nations.

Tommy's

32. Tommy's is a charitable organisation committed to saving babies' lives and supporting families through every part of the pregnancy journey. It was founded in 1992.

33. Tommy's funds pioneering research to identify why pregnancy goes wrong and to identify research breakthroughs with the potential to prevent loss and support healthy pregnancies. It also provides specialist care for people at the charity's clinics. Tommy's currently funds four specialist research centres across the country.

34. Tommy's provides expert, midwife-led advice for parents before, during and after pregnancy, working together towards safer, healthier pregnancies. This is delivered though Tommy's Pregnancy Hub, an online information-hub which provides a wide range of information about

having a safe and healthy pregnancy, from conception to birth. Tommy's also provides advice and support for families who have sadly lost babies. Tommy's is not a membership-based organisation. Tommy's operates throughout England, Wales and Northern Ireland.

Twins Trust

35. Twins Trust (formerly TAMBA, founded 1980) is the only UK-wide charity dedicated to improving the lives of families with twins, triplets or more.

36. Twins Trust ensures that every multiples' family can access the care and support it needs. Twins Trust runs courses, clubs and online community groups which bring people together. For people needing tailored support, it offers a peer-led helpline and family crisis support. Its specialist bereavement service supports people who have suffered a loss of twins, triplets or more, during or after pregnancy.

37. The aim of Twins Trust's work is to save lives and improve the safety of having a multiple pregnancy and birth in the UK. Twins Trust partners with clinicians, hospitals and maternity units to ensure that everyone expecting multiples has access to the best care. Twins Trust has approximately 18,000 members who pay a small monthly fee to access benefits including discounts and a magazine. However, Twins Trust supports families far beyond their membership. Its services are available throughout the UK.

II. IMPACT OF THE COVID-19 PANDEMIC ON PEOPLE WHO ENGAGED WITH EARLY PREGNANCY, MATERNITY, NEONATAL CARE AND SERVICES

A. Access to early pregnancy, maternity, neonatal care and services

38. During the pandemic, there were various forms of restriction on access to neonatal and early pregnancy and maternity services, including restrictions imposed by the Government, local authorities or local NHS services, all of which prevented access to certain pre-existing services. Furthermore, the pandemic had an impact on people's willingness or ability to seek access to care.

39. Although in many ways these restrictions impacted the different constituencies of each member of the PBPOs differently, as set out below, there are common themes that arise in respect of all early pregnancy, maternity and neonatal care services which repeat: the prioritisation of these services amongst other healthcare services; the inevitable distress caused by restrictions on the number of parents, family members and support partners who could attend hospitals (addressed below at paragraphs 129 – 170); and the availability of healthcare services once discharged from hospital. Although we want to share each member of the PBPO's unique experience and the unique experience of each of the PBPOs' members, supporters or service users, certain themes repeat in all of our stories.

Impact of Covid-19 fears on seeking all forms of early pregnancy, maternity care and services

40. Many of the PBPOs identified the uncertainty about the impact of Covid-19 on pregnant women and birthing people as having a significant impact on those who needed to engage with early pregnancy or maternity care or services during the relevant period. In particular, the inconsistent information about the impact of Covid-19 on pregnancy was a big cause of concern, as were the restrictions on direct contact with healthcare professionals. Each of the PBPOs has its own perspective on exactly how this was reported to it through its members or through the public seeking support, as we outline below.

41. During the relevant period, The EPT heard from women and pregnant people who were reluctant to seek medical attention. The EPT does not have a record of the precise numbers who contacted them with these concerns, but in subsequent stories, people expressed nervousness about contracting Covid-19 in hospital, worries about burdening the healthcare system, and difficulties in obtaining appointments if sought:

> Q1 - *"It was really only because I was worried about covid in the hospitals that I didn't go to A&E."*[2]

> Q2 - *"A day passed and I started feeling dizzy and the pain had got worse, reluctant to go to a&e in the current pandemic I new (sic) something was not right."*[3]

> Q3 - *"Due to covid and not being able to actually get an appointment with a doctor... My severe pain went from... Possible appendicitis to pelvic inflammatory disease this was by telephone consultations, then 3 weeks after the pain had started I was finally told I had an ectopic pregnancy and my tube had completely ruptured…"*[4]

42. Various studies produced since the pandemic have suggested that the pandemic overall did not cause delays in seeking medical assistance or result in worse outcomes for ectopic pregnancy assessment and management. Such studies considered (1) W*hether there were differences in the presentation and management of ectopic pregnancies in a major teaching hospital between 2019 (pre-COVID-19) and 2021 (COVID-19 period). The impact of COVID-19 on the assessment and management of ectopic pregnancies by Bethany Chung et al, Volume 4: Issue 1 dated 13 March 2023* **[Exhibit JW/1 – INQ000399364]**, (2) *Ultrasound characteristics, serum biochemistry and outcome of ectopic pregnancies presenting during COVID-19 pandemic, C. Kyriacou et al, 04 October 2021* **[Exhibit JW/2 – INQ000399375]**;

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[2] Anon Lived perspective from a supporter of The EPT.
[3] Anon Lived perspective from a supporter of The EPT.
[4] Anon Lived perspective from a supporter of The EPT.

and (3) *Impact of severe acute respiratory syndrome coronavirus 2 on ectopic pregnancy management in the United Kingdom: a multicentre observational study S Platts, J Ranawaka, et al 2021 Sep; 128(10): 1625–1634. Published online 2021 Jun 14* **[Exhibit JW/3 - INQ000399386]**. These studies covered data from UK tertiary units and teaching hospitals and are consistent in their findings. Similar studies for smaller hospitals would provide valuable data for application across ectopic pregnancy care across the UK of various resource levels.

43. Similarly, Pregnancy Sickness Support was contacted by sufferers of severe pregnancy sickness who, during the relevant period, did not wish to access healthcare services as they felt that their suffering was ‘unworthy’ of treatment because of the ongoing pandemic. The charity experienced a notable rise in calls from partners, relatives and friends calling on behalf of their pregnant loved ones who were refusing to seek help because they did not believe that their symptoms were serious and/or important enough to need any form of treatment at a time when, in their view, the NHS was at breaking point.

44. At the most extreme end of the spectrum, Pregnancy Sickness Support encountered HG sufferers who were experiencing all clinical signs and symptoms of dehydration but were deterred from seeking medical intervention because of (a) fear of contracting Covid-19 as the virus was unknown and the effects on pregnant women and birthing people were unknown and/or (b) the belief that treatment would be refused, based on previous experiences of rejection from health care professionals. Both pre and post-pandemic, referrals to hospital for HG could be difficult to achieve for women and pregnant people fighting against the perception (even amongst healthcare professionals) that hyperemesis is commonly “*just bad morning sickness*”. The anecdotal experiences of people contacting Pregnancy Sickness Support was that during a pandemic, it was even harder to get over these barriers. Especially for those who had previously experienced this rejection, the attitude was that if they were not believed pre pandemic when the health service was operating “*usually*”, what hope did they have of accessing treatment during a global pandemic. A sample of anecdotal experiences of people contacting Pregnancy Sickness Support during the pandemic has been provided by PSS and are set out below and also at **[Exhibit JW/4 - INQ000399397].**

> Q4 - *“I Due to the global crisis, the doctors will only speak on the phone. I feel really depressed and have never felt so rotten, I know this sounds weird, but I am petrified of being pregnant now this has happened. I think i can say that I am going through depression. I really need help. The doctors told me to contact my gp to get another anti sickness. I started crying because i cannot get through to my surgery..”*[5]

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[5] Anecdotal experience of Lauren who contacted Pregnancy Sickness Support during the pandemic provided by PSS.

Q5 - *"I don't want to end up hospitalized with all going on with Covid as well as my husband shielding and no care for my daughter as my parents are NHS workers.."*[6]

Q6 - *"with the coronavirus we are trying to stay away from the hospital and also the staff are overwhelmed but her sickness is non-stop from morning till night."*[7]

Impact of Covid-19 on access to appropriate treatments/care

45. Again, some of the specific ways in which Covid-19 affected access to appropriate care and treatment are outlined below (for example, at Section II(B) below on access to miscarriage and ectopic pregnancy support and care). In general, however, Baby Lifeline in their "Mind the Gap 2021" report **[Exhibit JW/5 - INQ000399402]** note that MBRRACE-UK found that improvements in care may have made a difference for 7 in 10 women who died with Covid-19 whilst pregnant or in the immediate post-pregnancy period. The latest MBRRACE-UK report (updated in 2023) updates that figure to 76 per cent, or 7.6 in 10 women. [**Exhibit JW/6 - INQ000399403**].

46. The PBPOs do not seek to entirely repeat the conclusions of the MBRRACE report here but note the top-line conclusions that multiple women who died from complications of Covid-19 whilst pregnant or in the immediate post-pregnancy period were not managed according to guidelines set out by the Royal College of Obstetricians and Gynaecologists (RCOG) and there were multiple examples of inappropriate care which resulted from a lack of understanding of treatments that could be used in pregnancy. In particular, the care women did receive was typically inappropriate due to a lack of understanding of what interventions and treatments, such as steroids, tocilizumab or ECMO, could be used in pregnancy. Cultural and structural biases further contributed to mismanagement of care during 2020 and 2021 (see Section VI below). Baby Lifeline consider that these serious impacts on women during the pandemic were attributable to systemic failures: evidence-based guidelines that were rapidly produced on treatment and care should have been clearly communicated and made easily accessible to frontline staff, as they were already overstretched during the pandemic. There were also gaps in training on care plans in certain maternity units, which would have been a good opportunity to upskill professionals to optimise care.

47. The PBPOs have considerable views on the steps that they consider could and should have been taken during the pandemic to try and address the fears and concerns of pregnant women and people which prevented them accessing medical support during the pandemic and also the real practical barriers to accessing treatment. In general, women and birthing

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[6] Anecdotal experience of Hayley who contacted Pregnancy Sickness Support during the pandemic provided by PSS.
[7] Anecdotal experience of Joanna who contacted Pregnancy Sickness Support during the pandemic provided by PSS.

people's fears arose in large part due to the Government and other official bodies' poor communications about what pregnant women and birthing people should or were allowed to do. The concerns about access to appropriate treatment and care were likewise in large part attributable to failures to communicate between frontline workers and those making policies and guidance, which led to misunderstandings about the care and treatment which should have been available. Put simply, healthcare workers were not given the support they needed to ensure pregnant women and birthing people received the necessary treatment and care they needed and were entitled to receive.

48. These recommendations are set out in the final section on "Lessons Learned". However, two of the PBPOs, by way of a summary, set out below some steps which could have been taken. In particular, The EPT consider that steps should have included:

    (a) Clear, dedicated messaging about actions healthcare settings were taking to reduce Covid-19 transmission risk;

    (b) Messaging directed to women and people encouraging them to seek medical attention if experiencing abdominal pain/vaginal bleeding, particularly if they might be pregnant;

    (c) Providing reassurance that attending medical appointments or seeking medical help was valid and necessary where pregnant women and people had non-Covid symptoms which needed investigating;

    (d) Clarity on how to obtain hospital appointments and on what steps were needed to reduce Covid-19 transmission when attending those appointments;

    (e) Ensuring the ability to attend appointments with trusted support people; and

    (f) Working with patient-facing organisations to disseminate messaging.

49. Further to that, Baby Lifeline concurs and adds that, in terms of prevention and mitigation of the impacts on pregnant women and birthing people, reasonable steps should have included:

    (a) Ensuring pregnant women and birthing people were included in medical trials and treatment programmes for Covid-19;

    (b) Messaging and communication directly to medical professionals (and training as needed) on the frontline on managing maternity and pregnancy care within the Covid-19 pandemic;

    (c) Ensuring up-to-date evidence-based guidelines were made readily available to frontline staff, given that this was a rapidly evolving situation;

    (d) Maintaining better staffing on maternity units, with minimised redeployment, given that maternity units cannot control their workloads in the same way as other departments.

Where redeployment has had to take place, ensure that professionals are fully trained and confident in areas that they have not worked in before, or for a long time;

(e) Vaccine rollouts and information for pregnant women and people should have been better communicated to those in primary care, midwives, and obstetric teams to better advise pregnant women and birthing people. While we appreciate that this will primarily be dealt with in the Vaccines module, front-line staff did not have the tools they needed to assist pregnant women and birthing people with the tide of misinformation online.

B. The management of miscarriages and ectopic pregnancies

Miscarriages

50. Tommy's noticed that in the period of March – August 2020, Tommy's midwives received a 40% increase in email enquiries, as an increasing number of anxious pregnant women and people sought help and support from a trusted source at a time when the NHS was not in a position to provide the level of reassurance, advice and guidance to women and pregnant people that they had in the past due to the pandemic pressures. Tommy's considers that as a consequence of the Covid-19 pandemic, women and pregnant people were discouraged from visiting hospitals or antenatal services unless absolutely necessary and routine appointments and scans were cancelled, reducing their access to information. In reality, Tommy's considers that women were being encouraged to miscarry at home.

51. Other organisations also report reluctance amongst pregnant women and birthing people to attend hospitals. Generally, and with reference to the case studies and quotes this statement refers to throughout, organisations advised that these women and people were worried about catching Covid-19 in hospitals; were reluctant to visit A&E clinics because of the fear it would be overrun due to the pandemic and the risk of catching Covid-19; and were also discouraged because of the sheer impossibility of getting medical appointments. The general messaging of "stay home, protect the NHS" was seen as generally discouraging people from getting routine medical support even if they needed it.

52. In May 2023, The Miscarriage Association carried out a survey **[Exhibit JW/7 - INQ000399404]** of 570 of its stakeholders, all of whom had been affected by pregnancy loss (or suspected pregnancy loss) between 1 April 2020 and 4 July 2021, the date final Covid restrictions were scheduled to be lifted. The Miscarriage Association shared the survey questions with their stakeholders and those who engage with them via their communications channels. Everyone was asked a qualifying question to ensure that they had experienced pregnancy loss during the period 1st April 2020 to 4th July 2021. The questions were designed to be non-leading questions and to gain an understanding of the different aspects of care and support that may have been affected during the identified period. The survey identified the

following key issues in respect of the management of miscarriages by maternity services during that period:

Reduced access to face-to-face care, particularly scans and assessments.

53. This included people who sought care due to pain, bleeding and/or other concerning symptoms (or lack of symptoms) during pregnancy, those with planned or routine appointments, especially dating or anomaly scans or those booked due to previous pregnancy loss, including ectopic pregnancy.

54. While the majority of those surveyed by The Miscarriage Association were able to access hospital care, 10% stated that they were unable to be seen in person. Of those unable to be seen in person, 75% were given advice over the phone, but 25% said they were unable to access any care at all.

55. Some examples of the responses to The Miscarriage Association's survey are provided below:

> Q7 - *"I had a missed miscarriage. I had to pay for a private scan. I then haemorrhaged at home, requiring emergency surgery and was in resus[citation], extremely unwell. It was a traumatic experience and I now fear another pregnancy."*[8]

> Q8 - *"I had a really drawn-out experience in which I had to go to multiple GP surgeries and hospitals to confirm my miscarriage as appointments were so scarce. I was also dismissed by the doctor in A&E as being dramatic regarding spotting in my 8th week of pregnancy. From there, it took almost 3 weeks to diagnose a missed miscarriage, and a further week for my treatment to be booked. As it was, I miscarried naturally on the day of my appointment, at home, where I was scared and in pain. I rang the hospital and they simply told me to take paracetamol. I still have flashbacks and nightmares regarding this, even following the birth of my healthy child."*[9]

Severely reduced ability for partners, or important others, to attend appointments

56. Having to attend appointments – and being given unexpected and/or upsetting news – while alone was, in The Miscarriage Association's view, the most distressing aspect of the care women and pregnant people received during the pandemic. This is addressed below at paragraphs 161 – 168.

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[8] Anon The Miscarriage Association stakeholder.

[9] Anon The Miscarriage Association stakeholder.

Reduced options for management of 'missed' or incomplete miscarriages

57. A 'missed' or 'silent' miscarriage is one where the foetus has died or not developed, but has not been physically miscarried. An incomplete miscarriage is when a miscarriage begins, but the pregnancy does not completely come away from the womb. Good practice in the management of 'missed' or incomplete miscarriages is for women and pregnant people to be offered a choice of management options – expectant (allowing nature to take its course), medical (tablets or pessaries) or surgical, under a general or local anaesthetic. During the pandemic, these options were severely limited – with access to surgical management, especially, being very restricted – causing additional pain and distress.

58. Of those surveyed by The Miscarriage Association, only 58% were given a choice of treatment, with 40% saying they ultimately did not receive their preferred management method.

59. There was also insufficient information on what to expect in terms of pain, the amount of bleeding and how to manage it, what the woman or pregnant person might see during the miscarriage, and what to do with their baby or pregnancy remains. Four of the comments provided to The Miscarriage Association in its survey are set out below:

> Q9 - *"I had to attend all appointments on my own, partner not allowed even on phone, having to remember and then repeat the words was awful. I was given very limited options for missed miscarriage as surgery was only once a week and list became full so it was wait or medical management at home. I had a toddler, childcare closed and had to take medical management alone upstairs, bleeding on the bathroom floor while parent looked after toddler, called ward for help but told to stay at home, had to keep any 'product of miscarriage' in the fridge for 2 days before being allowed to go in to clinic. Hadn't worked so had to wait another week for surgery. Emotionally scarring. Still very affected by this experience."*[10]

> Q10 - *"After suffering a missed miscarriage at 13 weeks I was advised to opt for medical management as non-emergency surgeries weren't offered during the pandemic … I was left to pass the foetus alone in a room before my BP crashed. I was taken into a room to have a speculum inserted and my cervix and womb emptied with forceps … no pain relief. Eventually it ended in an emergency D&C (surgical procedure). This was 9 months after a miscarriage at 22 weeks which only added to the trauma and PTSD."*[11]

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[10] Anon The Miscarriage Association stakeholder.

[11] Anon The Miscarriage Association stakeholder.

> Q11 - *"I was left in pain for hours with no pain relief. Unable to have surgery due to covid 19. My miscarriage was manually removed. This has had a big impact on how I have been feeling over the last 3 years."*[12]

> Q12 - *"Ended up waiting 3 days in hospital for surgery 4 weeks after finding out I had a missed miscarriage. I was told surgery was not an option originally due to covid and ended up with an infection. I then had to go back in for retained product. My husband was not allowed with me for any of this and the treatment from staff felt very inhumane. Was not allowed to eat or drink each day whilst I waited for surgery whilst still having pregnancy symptoms such as vomiting."*[13]

<u>Disruptions to investigations following recurring pregnancy losses</u>

60. During the pandemic, The Miscarriage Association also noted a negative impact on those experiencing recurrent miscarriage, and for those experiencing fertility issues, with cancellations to appointments, followed by slow and patchy resumption of investigations and treatment. Three of the responses to its survey are provided below:

> Q13 - *"When I was eventually given a referral for the recurrent loss clinic, it was for a date … 13 months after my last loss. I came away from the experience with the feeling that nobody really cared. I'm now pregnant after loss (having received private fertility treatment) and the first few experiences of attending hospital have been deeply traumatic. All the care and attention I receive while pregnant (although fantastic) makes me furious about the total absence of care I received beforehand."*[14] *Anon.*

> Q14 -*"I had barely any interaction after - I should have seen the recurrent loss clinic with this my third loss. But they just called and said I had to reduce my BMI and would help next time I was pregnant."*[15]

> Q15 - *"I had to wait a considerable amount of time for them to agree to begin the process of referring me for recurrent miscarriage tests because they didn't want any "non-emergency" cases to come to physical appointments, so I had to really fight for them to even do the blood tests to get the ball rolling."*[16]

<u>Lack of information, empathy and follow-up care</u>

61. The Miscarriage Association acknowledges that these are issues that are frequently reported by women and pregnant people at any time, but, in the Association's experience, tensions

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[12] Anon The Miscarriage Association stakeholder.
[13] Anon The Miscarriage Association stakeholder.
[14] Anon The Miscarriage Association stakeholder.
[15] Anon The Miscarriage Association stakeholder.
[16] Anon The Miscarriage Association stakeholder.

were far higher amongst patients and staff during the pandemic, with more people feeling unsupported, uninformed, uncared for and alone:

> Q16 - *"I was treated awfully, left alone in a room, no information, no one explaining things or offering support. No offer of a drink or food. I was left in a room with no windows and the door closed. Told through a gap in the door that I had to have surgery or I would die and then left alone again. No support no explanation and no discussion"*[17]

> Q17 - *"Being alone in scans and appointments was tough. Was my first pregnancy and had two further loses (incl surgery) during the pandemic. I had medical management for my first loss and was sent home. Suffer PTSD from the experience after being told 'expect a period bleed'. No aftercare was provided and I was handed a card with your (Miscarriage Association) number on it. That was it. Very, very scary."*[18]

62. Overall, The Miscarriage Association found that there was a clear dissatisfaction with the management of miscarriages during the pandemic. Of the 570 women and pregnant people surveyed by the Miscarriage Association, 8% said they were satisfied, 31% said they were somewhat satisfied, 28% were dissatisfied, and 34% were very dissatisfied.

63. Furthermore, 75% of respondents said that they felt that the care they received during this time was still impacting as at the date of the survey between 16th – 22nd May 2023.

Ectopic pregnancies

64. An ectopic pregnancy can be life-threatening for a woman/pregnant person if not diagnosed and treated quickly. The EPT works hard to raise awareness of symptoms and encourages women/pregnant people to seek medical attention fast. Early diagnosis can also mean more treatment options are available rather than emergency surgery.

65. The EPT is aware of at least six women who died due to an ectopic pregnancy during the pandemic and the charity is supporting their loved ones. There has been one year of relevant surveillance study on maternal deaths and morbidity covering the pandemic which addresses ectopic pregnancy[19] - that surveillance study is the MBRRACE collaboration's '*Saving Lives, Improving Mothers' Care Report - Lessons learned to inform maternity care from the UK and Ireland Confidential Enquiries into Maternal Deaths and Morbidity 2018-20'*, published

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[17] Anon The Miscarriage Association stakeholder.

[18] Anon The Miscarriage Association stakeholder.

[19] Although there have been other MBRRACE reports, referred to elsewhere in this statement, the reports cover different topics on an alternating basis.

November 2022 [**Exhibit JW/8 - INQ000399405**]. This report includes information on women who died during and after pregnancy from 2018 to 2020 and accordingly covers the first year of the pandemic, 2020. Such report indicates the UK death rate from ectopic pregnancy increased as compared with the previous report. The 2022 report stated that 8 women died due to ectopic pregnancy during the report period 2018-2022, an increase from the 5 women who died in the period 2015-2017 covered by the previous report from 2019. It is not possible to state whether this increase was related to Covid-19 restrictions but there may be more information about ectopic pregnancy in the next surveillance report.

66. Generally, there are three main treatments for ectopic pregnancy: (1) surgical management; (2) medical management with a drug called methotrexate; and (3) expectant management (also known as conservative management or watchful waiting). Medical management and expectant management are non-surgical treatment routes where tests are carried out to determine patient suitability, principally measuring beta hCG (human chorionic gonadotrophin, chemical created by pregnancy tissue) and ensuring the patient is haemodynamically stable. If deemed appropriate, non-surgical treatment involves having blood tests over a number of weeks to monitor beta hCG until the level returns to non-pregnant levels. In terms of operative techniques, surgery is usually via keyhole (laparoscopy) or can in some cases be open (laparotomy). Keyhole surgery is less invasive than open surgery, often with quicker physical recovery. During the initial stages of the pandemic, The EPT was made aware of (1) reduced access to non-surgical treatment routes; and (2) reduced access to laparoscopic or keyhole surgery.

Reduced access to treatment routes

67. Access to treatments for ectopic pregnancy changed during the pandemic. On one of the first days of lockdown (26 March 2020), The EPT was contacted by a consultant from a Cambridgeshire hospital who stated that availability of non-surgical treatments was being impacted depending on emergency care provision locally. If an NHS Trust was in a position to provide emergency care, non-surgical management was still being offered and follow-up appointments for blood tests were continuing.

68. However, if a setting was unable to offer emergency care, then non-surgical treatments might not have been available, unless units were able to refer to another hospital for emergency care. This meant that non-surgical treatment options depended on where a woman/pregnant person was located and treatment choice for women/pregnant people in certain areas was reduced. Covid guidelines suggested that conservative management should be adopted if possible and laparoscopy was thought to be hazardous at first due to aerosol production. Guidance stated: "*Patients should be managed in accordance with local protocols, with an emphasis on conservative management, if possible*". *ISUOG Consensus Statement on rationalization of early-pregnancy care and provision of ultrasonography in context of SARS-*

CoV-2. Bourne T, Kyriacou C, et al. 2020 June **[Exhibit JW/9 - INQ000399406]** *and Guidance for rationalising early pregnancy services in the evolving coronavirus (COVID-19) pandemic v.2, Royal College of Obstetricians & Gynaecologists, published 25 May 2021* **[Exhibit JW/10 - INQ000399365]**. This is covered in more detail below.

Reduced access to laparoscopic (keyhole) surgery

69. As part of the conversation on 26 March 2020 with a consultant from a Cambridgeshire hospital referred to above at paragraph 67, the consultant informed The EPT that her particular Trust had paused laparoscopic (keyhole) surgery while guidance to address possible infection risks was being drawn up. Laparoscopic surgery involves insufflation (blowing) of gas into the abdominal cavity and, as confirmed in the guidance subsequently published on 30 May 2020 by the Royal College of Surgeons of England (RCSENG) (*Updated Intercollegiate General Surgery Guidance on COVID-19, 30 May 2020, paragraph 6* **[Exhibit JW/11 - INQ000399366]**), there was *"concern about uncontrolled release of pressurised gas in laparoscopic surgery"* for infection control reasons. A study published in August 2020, *Laparoscopic Surgery and the debate on its safety during COVID-19 pandemic: A systematic review of recommendations by Michael El Boghdady and Beatrice Marianne Ewalds-Kvist published online 2020 Aug 11* **[Exhibit JW/12 - INQ000399367]**, reviewed literature regarding the safe use of laparoscopy during Covid-19. It concluded: "If possible and safe, conservative management is the primary alternative during the pandemic. Based on our review, we concluded that recommended precautions should be respected while performing laparoscopy during COVID-19 pandemic to protect [healthcare workers] from possible aerosolised virus contamination."

70. Because of safety concerns, for a period of time from approximately 26 March 2020 until precautions were implemented in units as per RCSENG guidance issued on 30 May 2020, the availability of laparoscopic surgery was reduced with some women/pregnant people being able to have open surgery only (laparotomy). This included in cases where the pregnancy could not be located either in the womb or elsewhere via a transvaginal ultrasound scan (known as a Pregnancy of Unknown Location or PUL) and exploratory surgery was needed. Until guidance was issued on 30 May 2020 and units "cautiously re-established laparoscopy where all criteria [for risk mitigation] are met", the more invasive laparotomy procedure was the only surgical route for diagnosis and treatment purposes in some hospitals. The speed and extent to which RCSENG's guidance was followed by hospitals would likely have been variable, depending on resources and capacity. Anecdotally, many hospitals did not sort out appropriate safety issues relating to laparoscopic surgery.

71. On 3 April 2020, the Royal College of Obstetricians and Gynaecologists (RCOG) and the International Society of Ultrasound in Obstetrics and Gynaecology (ISUOG) issued guidelines to rationalise early pregnancy and gynaecological ultrasound services during the

pandemic. The guidelines stated that a scan should be carried out within 24 hours for women with risk factors or symptoms of ectopic pregnancy. Telephone triage was introduced to determine whether women or pregnant people would need to attend hospital for assessment of early pregnancy complications as set out in *ISUOG Consensus Statement on rationalization of early-pregnancy care and provision of ultrasonography in context of SARS-CoV-2. Bourne T, Kyriacou C, et al. 2020 June* **[Exhibit JW/9 - INQ000399406]** and *Guidance for rationalising early pregnancy services in the evolving coronavirus (COVID-19) pandemic v.2, Royal College of Obstetricians & Gynaecologists, published 25 May 2021* **[Exhibit JW/10 - INQ000399365]**.

72. The EPT is aware of studies considering access to early pregnancy services for ectopic pregnancy care. In particular, one study, *Ultrasound characteristics, serum biochemistry and outcome of ectopic pregnancies presenting during COVID-19 pandemic, C. Kyriacou et al, 04 October 2021* **[Exhibit JW/2 - INQ000399375]**, found that no difference was observed in the location, size, morphology or gestational age at the first ultrasound examination or at diagnosis of ectopic pregnancy between women diagnosed before vs during the COVID-19 pandemic. It concluded that hCG levels and the failure rate of first-line conservative management measures were higher during the pandemic but that women continued to access appropriate care for EP during the COVID-19 pandemic, with no evidence of diagnostic delay or an increase in adverse outcome in our population. Another study, *Impact of severe acute respiratory syndrome coronavirus 2 on ectopic pregnancy management in the United Kingdom: a multicentre observational study S Platts, J Ranawaka, et al 2021 Sep; 128(10): 1625–1634. Published online 2021 Jun 14* **[Exhibit JW/3 - INQ000399386]**, found that women underwent significantly higher rates of non-surgical management during the Covid-19 first wave compared with a pre-pandemic cohort, but that higher rate of non-surgical management of ectopic pregnancy during the Covid-19 pandemic did not increase complication rates.

73. Notwithstanding this, The EPT was informed of individual instances of ectopic pregnancies where hospital transfer/access was not a given, even with medical professionals in attendance. For example, this case study is taken from an EPT online message-board:

> Q18 - *"It took two visits from paramedics (within 24 hours) before they decided it was likely an ectopic pregnancy and I needed to go to hospital. Luckily there was no queue for the ambulance getting into the hospital - but they did warn me this was a highly likely possibility. My husband was not allowed to come in the ambulance with me because of the pandemic, which made me very anxious."*[20]

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[20] Anon case study from The EPT online message-board.

C. Access to early pregnancy, maternity and neonatal services, including home births and/or birth centres

74. Overall, in the PBPOs' experience, access to early pregnancy, maternity and neonatal services became more restricted during the Covid-19 pandemic and with the attendant restrictions on face-to-face contact with healthcare professionals. The PBPOs found that Covid-19 and the pandemic restrictions affected access to services within hospitals, support for parents and babies on discharge, and specialist support for women and pregnant people after birth. Ultimately, these themes are interlinked and overlap: there was a general absence of the typical support required for new families from antenatal care to post-discharge care.

Access to services within hospitals

75. Like the other charities, NCT heard widespread feedback from expectant parents about midwifery units being closed and home birth services suspended. Although NCT did not directly keep records of this, the feedback it received is supported by a Royal College of Midwives (RCM) survey finding on 29 March 2020, *RCM plea: Help us deliver safe care for pregnant women dated 29 March 2020* **[Exhibit JW/13 - INQ000399368]** in which it reports that: *'Over a fifth (22%) of survey respondents reported that local midwife-led maternity units had been closed, with more than a third (36%) of areas also either stopping (32%) or restricting (4%) homebirths. In 11 cases the midwife-led unit has been closed to provide facilities to assess or care for coronavirus patients'.* This also correlates with the responses received in the NCT 2022 survey, 'Women's Experiences of Maternity Care'.[21]

76. NCT was also alerted by members to very concerning announcements from health authorities, such as the Greater Manchester and Eastern Cheshire Local Maternity System, which in August 2020 provided guidance, *GMEC Unassisted Birth During the Covid-19 Pandemic Guidance dated 14 August 2020* **[Exhibit JW/14 - INQ000399369]**, about unassisted births and Covid-19-driven limits on support for such services as follows:

> *"As a result of service pressures in maternity and related services including the ambulance service during the Covid-19 pandemic, some maternity services have made the difficult decision to suspend the availability of home birth and/or midwife-led birth in some areas. … Some women will find the alternative options on offer unacceptable or feel that they do not meet their needs and may choose to have an unassisted birth. Women may feel that unassisted birth is the only way that they can retain choice, control and autonomy during the birth process. Other reasons may be due to the woman's concerns that the baby may contract the Covid-19 virus, or they fear that their partner may not be able to be with them during labour and the birth,*

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[21] The references throughout are drawn from the NCT's own data which can be provided to the Inquiry on request.

> *particularly where the partner has symptoms of Covid-19. The concern from maternity services is that birthing without midwifery assistance brings with it increased risks to both the mother and baby".*

77. Choice of birth setting is, in normal situations, a key part of maternity policy to enable women and birthing people's autonomy and control over a safe birthing event. However, during the early pandemic, when home birth services were widely suspended, it became clear that women and birthing people – because of the lack of choices available – were putting themselves and their babies at risk by avoiding or declining the services of either midwives or medical staff. The recognition in August 2020 from the Greater Manchester and Eastern Cheshire Local Maternity System, an NHS England body, that women and birthing people were choosing 'unassisted' birth to avoid entering a hospital was significant. It indicated there were more than just isolated cases of such decisions, which ultimately led to women and birthing people birthing without skilled care.

78. As noted above, NCT carried out a survey of over 1,200 new parents in 2022 on their experiences in the past year, aiming to identify where staffing shortages had caused delays or other shortfalls in care, using the NICE 'red flag' system. The survey was live from 13 July 2022 to 27 July 2022. Anyone who had given birth from August 2021 to July 2022 were asked about their experiences of care from different cadres of maternity professional staff, including midwives, obstetricians, anaesthetists and sonographers.

79. The aim was to help provide evidence for a campaign to call for improved maternity staffing being launched by two APPGs, that for maternity and that for baby loss. Over 1,200 people consented to participate in the survey. Varying numbers of people answered each question depending on whether it was relevant to them. Respondent numbers ranged from 833 people answering questions about their experience with midwives through to 26 people answering questions about the postnatal care they received from a sonographer. Not all staffing problems were necessarily a consequence of the Covid-19 pandemic, but redeployment, sickness and burnout appeared to have had a serious impact. Overall, 51% of people who completed the survey reported experiencing at least one NICE-identified red flag event during their intrapartum care. Concerningly, however, of the people who indicated they had experienced a red flag event, 48% had been affected by two or more events and one third (33%) experienced four or more events.

80. One respondent said:

> Q19 - "*In my birth plan I had requested a water birth and an active birth. This was not possible, but again, no midwife explained why I couldn't do this or even appeared to acknowledge my birth plan*"[22].

81. Other typical findings were:

    (a) 42% had to wait more than 30 minutes to be assessed after alerting a midwife to a problem during/after labour.

    (b) 39% had to wait more than 30 minutes for pain relief during labour.

    (c) 36% experienced a delay in getting a prescription for medication.

    (d) 35% reported delays in staff noticing or acting on signs that they had (or might have had) a serious health problem.

82. In comparison to the situation in pre-Covid years, an NCT report from 2017 titled *Support Overdue: Women's experiences of maternity services 2017, author Lisa Plotkin* **[Exhibit JW/15 - INQ000399370]** suggests that in 2017, 31% of women had delay in getting pain relief in 2017 and 28% had delay in getting a prescription.

83. During the relevant period, NCT consistently issued public calls, in collaboration with other charities and parent groups, for closer attention to be paid to the needs of families, especially those with new babies as demonstrated by *NCT's response to the Maternal Mental Health during a Pandemic Report dated 19 March 2021* **[Exhibit JW/16 - INQ000399371]**.

84. During neonatal hospital admissions, in Bliss's experience, face-to-face attendance at regular (daily or weekly) ward rounds is important for parents and caregivers. This is an opportunity for them to hear about their baby's condition and treatment plan from the clinical team. Increasingly, parents are now supported to be actively involved in ward rounds, including by introducing their baby to the clinical team and asking questions. A survey carried out by Bliss, *Locked out: the impact of Covid-19 on neonatal care* **[Exhibit JW/17 - INQ000399372]** found that this practice was severely disrupted during the pandemic. Most NHS Trusts that responded to Bliss's survey said that parents were either unable to attend ward rounds at their unit, or that only one parent could attend. This led to parents feeling unsupported while receiving bad news and feeling overwhelming responsibility to communicate complex medical information accurately to the baby's other parent. For the parents not able to be present, they were unable to ask questions or be as involved in care and decision-making as they wished to be.

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[22] Anon NCT Parent.

> Q20 - *“[I felt] depressed and upset as we didn’t know if our twin 2 would survive. She had a major heart defect and when in intensive care on a ventilator I had absolutely no support. I wasn’t allowed my partner in with me which was absolutely horrific [as] we didn’t know if she would make it. It’s had a very traumatic effect for myself and my partner.”*[23]

> Q21 - *“Having to talk to consultants alone with[out] the support of a partner when discussing whether your baby was going to live. Having to stand there ALONE as they resuscitated your baby without your husband by your side. This was detrimental to my breast milk supply and my mental health as this went on for 119 long days.”*[24]

> Q22 - *“[My partner] became severely depressed whilst being kept from them. He spent 9 weeks away, with his last conversation with their consultant being how they weren't expecting our smallest to make it. That tormented him for the entire time before he was allowed back. When he finally was [able to go on the unit] they were four times their birth size and totally different babies.”*[25]

85. Bliss was also aware anecdotally of knock-on capacity challenges which could delay discharge from hospital. For example, Paediatric Intensive Care Unit (‘PICU’) capacity was reduced due to the extreme pressures being placed on adult intensive care wards. Some babies will need to be admitted to PICU during a neonatal admission (for example, if they need surgical care) so, in Bliss’s experience, there was some knock-on impact to them of this reduced capacity.

86. During the pandemic, Aching Arms’ Bereavement Care Manager was employed part-time by a local NHS Trust as a Bereavement Midwife Support Assistant. She informed Aching Arms that, on a local level, bereavement suites were being used as Covid-19 isolation rooms and the normal level of care provided by the specialist midwife bereavement team was severely curtailed. She was no longer able to do home visits to newly bereaved families due to the national guidance preventing visiting other families in their homes. All home visits across maternity care were stopped. With midwives being used to cover other areas of clinical need and shorter hospital stays for parents after their baby has died, Aching Arms found that overall there was less support available to bereaved parents.

87. ICP Support report that during the pandemic women and pregnant people reported being refused vital blood tests because of the restrictions imposed in the pandemic. These blood

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[23] Anon mother of twins born in June 2020.
[24] Anon mother of a baby born in April 2020.
[25] Anon mother of twins born in March 2020.

tests (bile acid blood test) are the only way to diagnose ICP and also assess fetal safety (because at high concentrations bile acids can cause stillbirth). ICP do not have any figures on the numbers of people who were refused these tests. These tests can only be carried out in a hospital lab. It would have been possible for women to go to their surgery to have the blood drawn but this could have caused a delay in getting the results.

Access to maternity and neonatal care once discharged home

88. During the relevant period, Bliss became anecdotally aware of babies being discharged home more quickly, particularly in the early weeks of the pandemic, in order to manage capacity and best preserve the functionality of service. Discharge home can be a difficult time for families, and Bliss believes this experience would have been more difficult than usual as parents were denied time on the unit to be with and care for their babies. For babies discharged from hospital into lockdown, their families were very isolated. Some babies spent weeks or months in hospital only to go home and still be unable to meet some of their family members for months to come. In Bliss's experience it was also particularly difficult to transition to home given the absence of face-to-face support in the community.

89. Similarly, NCT observed that community staffing from midwives and health visitors was often affected by staff having been redeployed elsewhere, and for much of lockdown no home visits were possible. New parents could not legally meet other parents or even have their own close family members to help in the house. After partners finished a typical two-week paternity leave, many mothers and birthing people found themselves completely alone with their newborn for 10 or more hours a day.

90. The Lullaby Trust also observed that the midwifery service was under great pressure during the Covid-19 pandemic, which meant that they offered fewer face-to-face appointments. If appointments were offered, then because of Covid-19 restrictions, pregnant women and birthing people were alone and often virtual, or telephone appointments were carried out instead. This meant that the opportunity to recognise that a family had experienced a baby loss was limited, as was the time to discuss the parent's fears and anxieties, and the time to discuss the benefits of the Trust's flagship Care of Next Infant ('**CONI**') programme.

91. The CONI programme is a bereavement support programme which provides emotional support to families who have had a baby die and information about health issues such as sudden infant death syndrome and safer sleeping. The programme forms an integral part of the work of The Lullaby Trust and is delivered in conjunction with the NHS, local authorities and other providers of community public health services. Before Covid-19, midwives were the main route of referral into the programme. During the Covid-19 pandemic, the ability to deliver the CONI programme to bereaved families was severely impacted in the following ways:

a. contacting the local CONI Coordinator (a specially trained health visitor) was difficult due to the redeployment of health visitors to other roles, impacting their ability to carry out their workload, including the CONI programme;

b. social distancing measures meant that health visitors were unable to carry out home visits, or very limited visits, or only virtual or telephone contacts to provide emotional support, advice and clinically assess the baby;

c. reduced, or no access to, equipment stores and offices by health visitors who were working from home. This meant that they were unable to access resources needed for delivering the CONI programme such as baby movement (breathing) monitors, weighing scales, symptom diaries, specialised CONI weight charts and information leaflets. There were also difficulties with having the equipment serviced.

> Q23 - *"I would have liked more Health Visitor support visits, but due to COVID 19, am aware home visits were restricted.[26]"*

92. Enrolment numbers onto the CONI programme went from 102 in January 2020 and 143 in February 2020, to 43 in March 2020 and remained low during the pandemic. The enrolment numbers are yet to recover in 2023, due to the ongoing impact of the Covid-19 pandemic on maternity care/services. As is addressed below at paragraphs 170 -175, the Lullaby Trust took a number of steps to supplement the lack of access to face-to-face assistance including by providing significant assistance to health visitors.

Access to specialist medical support for pregnant women and birthing people

93. From the start of the UK lockdowns in March 2020, pregnant women and birthing people suffering from HG were plunged into an untenable position. They desperately needed access to medical treatment,[27] that due to the infrastructure of early pregnancy support, could only be accessed in hospital. It was particularly difficult to seek this support given the emphasis on containment, the vulnerability of pregnant people, and the lack of knowledge of outcomes from Covid-19 on both the mother/birthing person and the foetus. This had a detrimental impact on the ability to seek antenatal care and treatment and prompted a real concern from many pregnant women and birthing people over whether to access treatment at all.

94. Sadly, pre-pandemic, too many sufferers were already facing an uphill struggle to get access to quality care, treatment, and medication. Attitudes of health care professionals are often negative and reveal a lack of knowledge surrounding the condition. As noted above, their symptoms are often ignored and their suffering diminished. The COVID-19 pandemic exacerbated the difficulty for these women and birthing people accessing medication and

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[26] Anonymous quote from a CONI Parent.

[27] Treatments such as IV fluid replenishment to help with dehydration from lack of fluids due to excessive vomiting and nausea, IV anti-sickness medication and check-ups of both the mother and foetus were required to be undertaken in a hospital setting.

generally poor patient experience and outcomes. During the pandemic, any symptoms like "morning sickness" resulted in pregnant women and birthing people being seen as a low priority and potentially high risk if referred to a hospital.

95. During the relevant period, Pregnancy Sickness Support received a notable number of enquiries and comments around Covid-19 related issues. These included concerns around GP surgery closures, the move to telephone appointments, refused treatment and poor/refusal of care. A set of excerpts are set out at **[Exhibit JW/4 - INQ000399397]**.

96. At the start of the pandemic, government guidance led to the cessation of all face-to-face NHS physiotherapy, private physiotherapy, osteopathy and chiropractic appointments, leaving pregnant women and birthing people without any options for treatment for their pain. This left them suffering severe pain and disability.

97. Given the limited access to traditional healthcare appointments, pregnant women and birthing people were forced online to seek solutions to their healthcare issues, rather than consulting healthcare practitioners in person. For the Pelvic Partnership, this manifested in a significant upsurge in activity of 127% in the first half of 2020 on their Facebook support group as well as calls to their helpline increasing by 158%. Most comments were from pregnant and postnatal women/people with PGP asking for information, support and guidance on how to best manage and treat their pain, often without access to manual therapy or pain relief.

D. The use of online/remote access to early pregnancy, maternity and neonatal care and services;

98. Many of the PBPOs turned to online or remote access to provide their crucial maternity care and services. This is broadly addressed below at paragraphs 171 - 188 as much of this was in response to identified gaps in existing services.

99. The PBPOs have also outlined above how many crucial services became online or remote only. Although much of the PBPOs' information was received anecdotally, it is supported by data. For example, the RCM survey from March 2020 reflected Bliss' feedback in respect of neonatal care, finding that 78% of midwifery leaders reported ending routine face-to-face antenatal and postnatal visits, with a further 9% restricting face-to-face postnatal visits only.

100. Bliss heard anecdotally from healthcare professionals, and from parents, that video calls were utilised to enable parents to participate in ward rounds when they were unable to attend the neonatal unit. However, it is not known how widespread, or how effective, that practice was.

101. After discharge from neonatal care, face-to-face appointments were severely disrupted, and many neonatal follow-up or outreach appointments were delivered remotely via video call. These were subject to delays. Families also experienced a wider disruption to newborn services once they were discharged home – for example, disruption to home-midwife or health

visitor appointments, which either moved online or were cancelled altogether. Bliss heard from healthcare professionals that this could be difficult and that it was harder to assess a baby remotely than in person. It also significantly disadvantaged families who did not have good access to Wi-Fi, mobile data or equipment to enable these meetings to go ahead. This meant babies missed out on the same level of care they would have received had they been born outside of the Covid-19 pandemic.

Positive uses of technology and online services

102. There were some specific, positive uses of technology implemented during the Covid-19 pandemic. The first, in respect of neonatal care and identified by Bliss, was the successful roll-out of vCreate and other video-diary services, enabling parents to receive updates about their baby when they could not be on the unit due to access restrictions/other reasons.

103. As already noted, parental access to their babies in neonatal care was severely restricted from March 2020. vCreate was one remote technology employed to mitigate against this. This platform allows parents to see pictures and videos of their baby, as well as receive written messages and to send them back. Bliss understands that NHS England provided funding to all neonatal units to use vCreate during 2020-2021. The Scottish Government supported the roll out of vCreate to all neonatal units in Scotland, including provision of iPads for use on units. Bliss is unaware of the arrangements in Wales and Northern Ireland.

104. The EPT also found that the use of telephone triage for scheduled early pregnancy appointments appears to be safe and may offer a sensible approach to rationalising services and arranging appointment times. However, this is based on a single study, '*The impact of the Covid-19 pandemic on care of women with ectopic pregnancy in a tertiary London hospital' (Dec 2021)* **[Exhibit JW/18 - INQ000399373]**, which showed that there was a 36% reduction in attendance at one London-based nurse-led Early Pregnancy and Acute Gynaecology Unit during the pandemic, but that there was no significant difference in various factors including diagnosis rate, gestation at diagnosis, or in the rate of surgical intervention or complications. The study was based at a central London tertiary nurse-led Early Pregnancy & Acute Gynaecology Unit and larger studies and sites (including district general hospitals) are needed to collate data for feasibility, requirements, cost, resources and standards before any possible wider roll-out.

E. The way in which early pregnancy, maternity and neonatal care services were accessed

105. As noted above, the way in which early pregnancy, maternity and neonatal care services were accessed was a significant concern to many in the PBPOs. In particular, the issue of who could attend scans and hospital appointments was a significant concern. This is primarily addressed below at paragraphs 129 – 168.

106. Bliss identifies that other aspects of family-centred care delivery were significantly altered, including access to elements of neonatal care which are usually routine, for example the closure of parent accommodation, parent rooms and kitchens, and changes to access to expressing rooms meaning only one woman or birthing person could use the facilities at a time. Bliss is aware of neonatal services which stopped parents from using equipment such as toasters and kettles due to concerns about infection.

107. In Bliss' view, this affected families in two ways. First, it made it more difficult to be present on the unit if onsite facilities were not in use. Being unable to make a cup of tea or a simple sandwich also meant increased costs for parents who would need to purchase these refreshments off-site. Second, it increased parent isolation. The neonatal experience can be overwhelming and isolating at any time, but many parents build strong bonds with other families on the unit, often facilitated through having access to these shared spaces. The closure of these spaces, and implementation of social distancing and PPE requirements, made it very difficult for parents to connect with others and receive peer support.

108. Other support that would usually be available (e.g. free or discounted meals from the canteen) were not available because of the pandemic. For parents without access to a car, the guidance not to use public transport made travelling to the hospital (usually by taxi) even more expensive, as set out in Bliss' report *'Locked out: the impact of COVID-19 on neonatal care'*, **[Exhibit JW/17 - INQ000399372**] albeit that some other policies relating to the pandemic had lessened the financial burden, such as removal of parking charges during lockdown.

> Q24 - *"We stopped rooming in for a month in March 2020. Our exclusive breastfeeding rates dropped by half during that time."*[28]

> Q25 - *''There was support in place for us at the hospital but due to COVID we were not allowed to access this (canteen etc.)"*[29]

> Q26 - *"My baby had to be born in a hospital 2 hours from where we live. Due to Covid there was no accommodation and we needed to stay in an air bnb which was expensive."*[30]

109. In Scotland, the Scottish Government extended the remit of the then-Neonatal Expenses Fund to include the cost of taxi fares to reduce parents' exposure to the virus on public transport. 67% of the parents surveyed by Bliss who lived in Scotland said that they had been able to access support with expenses. Of those who could access this support, as set out in Bliss'

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[28] Anon staff member of a Local Neonatal Unit.
[29] Anon father of a baby born in July 2020.
[30] Anon mother of a baby born in October 2020.

report *'Locked out: the impact of COVID-19 on neonatal care'*, [**Exhibit JW/17 - INQ000399372**] 79% said it made a positive difference to them and their family.

> Q27 - *"It's an expensive time having a baby and the additional travel costs build up but being able to apply to receive some of the costs back was helpful."*[31]

F. Bereavement services

110. There was also disruption to bereavement services and processes during the pandemic.

111. Bliss identified significant changes where a baby died on the neonatal unit. In some cases bereavement facilities – including bereavement suites or private rooms – were closed for infection prevention reasons, or repurposed for another use. More information about the impact on bereavement care is outlined further in this statement.

112. As with other services, there was also disruption once bereaved parents were at home. For babies who died in the early days, weeks and months of the pandemic, parents were unable to access usual bereavement support from home (as face-to-face support was largely impossible), and wider societal restrictions, for example on in-person attendance at funerals, meant they were unable to say goodbye to their babies as they would have liked to:

> Q28 - *"We couldn't have visitors, no end-of-life support, no proper funeral, no after death support at all for the father (me) and my partner's was only a phone call."*[32]

113. Twins Trust report similar issues, and is, sadly, aware of many parents put in this position, given that rates of stillbirth and neonatal death amongst twins are significantly higher than singleton babies. There were many examples of parents not having the time, space or support to grieve properly, as well as the difficulties of having to support a live twin whilst coping with bereavement. The needs of, and support for, parents with multiples and their babies should have been more carefully considered. When separation occurs, particularly at this critical juncture, it increases the psychological strain on the family; that is true of adults being separated from one another, people being separated from their dead baby or babies and also the issues that arise when one or more babies survive and the other(s) die. If a decision has to be made to separate any strands of a family, particularly after a bereavement, due consideration and support (particularly familial support) needs to be put in place to contain the emotional impact:

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[31] Anon mother of a baby born in August 2020.

[32] Anon father of a baby who was born before March 2020, who died in neonatal care.

> Q29 - "*One twin spent 4 months in hospital before passing away. We were not allowed to have our twins together, it impacted breastfeeding, we were not allowed support from family and friends (we very much needed it!!!)*"[33]

G. Availability of healthcare staff to provide early pregnancy, maternity and neonatal care and services at home and in hospital settings

> Q30 - *"Due to midwife shortages my baby was delivered at the side of the road...The ambulance crew told us we were the second couple they had been to that night who had delivered en-route to the hospital."*[34]

> Q31 – *"Because my surgery ended up happening so late and because there were not enough porters to move patients from recovery, I didn't get back to my room until nearly 11pm (my scan was at 9am). So I spent the night and morning alone again until I was allowed to be picked up to go home."*[35]

114. The PBPOs have consistently raised concerns about the lack of availability of healthcare staff to provide crucial early pregnancy, maternity and neonatal care and services throughout the pandemic, due in large part to their redeployment to other parts of the healthcare system, as well as absences related to sickness, self-isolation and shielding. The impact of Long Covid on healthcare staff meant that periods of sickness were sometimes extended for longer than the isolation periods set, prolonging staffing difficulties. Regardless of the reason for the lack of availability of healthcare staff to provide early pregnancy, maternity care and neonatal services, the lack of attention on the resulting impact on maternity care and babies was of major concern to the PBPOs. Much of this is addressed above.

115. Within the PBPOs, the following consequences of the lack of availability of healthcare staff to provide maternity care/services were observed:

    a. Limited availability or virtual delivery of midwife and health visitor appointments meant that more families approached the Lullaby Trust's helpline for advice on safer sleep for their babies;

    b. Neonatal staffing levels were affected, including by the redeployment of allied health professionals, which led to limitations to the service being provided on the neonatal unit;

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[33] Anon parent.
[34] Anon NCT survey responder.
[35] Anon lived perspective from a supporter of The EPT.

c. Bliss observed that staffing pressures within maternity services had a knock-on impact on neonatal care, meaning in-utero transfers were not able to be coordinated, leading to some babies being born at a hospital without a NICU when this would have been optimal care;

d. The EPT found that women and pregnant people suffering early pregnancy loss felt that their experience was of little or no consequence, partially because of the lack of access to healthcare and hospital staff:

> Q32 - *"I wasn't seen by a doctor after the operation, which is a real shame. The unit had lots of emergencies that day, so I think they hadn't had time to talk to me about what happened, and what to do next (it was in the middle of the pandemic). I should have asked to have been seen, but I somehow didn't think of it at the time."*[36]

e. Studies, including (1) J Farren et al, '*Differences in posttraumatic stress, anxiety and depression following miscarriage or ectopic pregnancy between women and their partners: multicentre prospective cohort study' dated* October 2020; and (2) *Post-traumatic stress, anxiety and depression following miscarriage and ectopic pregnancy: a multicenter, prospective, cohort study by Farren J et al dated April 2020* [**Exhibit JW/19 - INQ000399374**] conducted prior to the pandemic have shown ectopic pregnancy is associated with increased risk of post-traumatic stress disorder, anxiety and depression for women/pregnant people and their partners. This may well have been exacerbated by the pandemic. The EPT also heard accounts of the mental health impact of the lack of healthcare staff contact:

> Q33 - *"I also sometimes feel a bit abandoned if that makes sense, like I was discharged physically, but there is no follow up appointment with anyone on my mental wellbeing. I wonder if that had happened it might not have boiled up the way it has. But then I know how stretched the staff have been during this pandemic so I can understand why."*[37]

> Q34 - *"There is a sense of nothingness, no follow ups, no guidance, not even a sick note from the hospital."*[38]

116. Given how hard many healthcare professionals worked during the pandemic in highly pressured circumstances, it is regrettable that some people's experiences during the pandemic

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[36] Anon Lived perspective from a supporter of The EPT.
[37] Anon Lived perspective from a supporter of The EPT.
[38] Anon Lived perspective from a supporter of The EPT.

have made them feel so let down that their trust in the healthcare system has been irretrievably impacted.

> Q35 - *"I spent the next 2 days stuck on that ward due to infection…My partner nor my colleagues who worked in the hospital were allowed to see me….Was given no information as to what to expect. The 'dissolvable' stiches are still there at almost 4 weeks post op and have now become infected (trousers catching on the stitches when I've returned to work). And I can't bring myself to contact them back. I feel angry, lonely and fobbed off by the professionals that were meant to take care of me. I've had so many problems in recovery that they seem entirely incompetent and I feel violently ill at the thought of going back there again. When I've phoned up demanding answers, I just got told it was because of the pandemic."*[39]

> Q36 - *"Although I understand that medical staff are under immense pressure these days, I still can't help but feel frustrated that there were two occasions (termination appointment and when I called them back after) when I could have been offered a scan, and my ectopic could have been dealt with before it came to it's (sic) life threatening peak."*[40]

> *Q37 - "Luckily, my surgery went without a hitch and my wife was allowed on the ward for an hour once I was back. Thankfully, I was also discharged the same day, so only had to be alone for 6 more hours or so. However, when I was discharged, I was discharged without a note for work, without pain killers and without follow up instructions."*[41]

> *Q38 - "I haven't had any follow ups from the hospital. No sign of my histology. I didn't even get to speak to my surgeon about how it went. So I requested my notes and am horrified to have not been told about some of their findings. Filmy adhesions and endometriosis for example... kind of important to know but they made no mention of it."*[42]

117. The NCT 2022 survey, 'Women's Experiences of Maternity Care', included the responses:

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[39] Anon Lived perspective from a supporter of The EPT.
[40] Anon Lived perspective from a supporter of The EPT.
[41] Anon Lived perspective from a supporter of The EPT.
[42] Anon Lived perspective from a supporter of The EPT.

> Q39 - *"I was told there was no space…and they had to call around to find somewhere. I can't even begin to describe how detrimental and traumatising this was to my birthing experience..."*[43]

> Q40 - *"I was unable to give birth in my desired birthing unit due to staff shortages, which led to (us) needing to travel a further 40 minutes. I gave birth at the entrance of the hospital due to this, at a hospital I'd never been to before."*[44]

118. Despite all the concerns raised, The Miscarriage Association and The EPT both received comments from healthcare staff who struggled with the restrictions and sometimes found ways around them, for example by bringing a partner in through a back door to support the person who had received bad news following a scan.

119. Other healthcare staff commented that they simply felt unable to provide the care they thought was needed:

> Q41 - *"The hospitals I have worked in during the pandemic have generally kept EPU services going, especially given that ectopic pregnancy is a time critical condition, but access to procedures/surgery for pregnancy loss has been reduced and I have found it difficult to explain to patients that they have to wait longer for management of their pregnancy loss as I empathise and understand people want 'to move forward. I would describe a feeling of personally feeling 'helpless' in this situation and often I chat this through with my colleagues and find this is useful".*[45]

120. Comments provided to The Miscarriage Association, by people who had accessed the limited maternity services available during the pandemic, reflected and acknowledged the burden on healthcare professionals during this time, for example:

> Q42 - *"I had recurrent miscarriages during covid. In one hospital they let my husband stand in the fire door (he had to push through bushes to get round the building) so that he could be there for me as they explained what to do. Individual staff were amazing, but it was really hard."*[46]

H. Use of PPE in early pregnancy, maternity and neonatal care and services

121. In the PBPOs' view, the use of PPE in early pregnancy, maternity and neonatal care and services during the pandemic had three major negative impacts: first, on communication

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[43] Anon NCT survey responder.

[44] Anon NCT survey responder.

[45] Anon Nursing Professional talking to The EPT.

[46] Anon The Miscarriage Association stakeholder.

between new parents and their babies; second, on communication between healthcare staff and new parents; and third, on the wellbeing of pregnant women and birthing people who were experiencing grave sickness, such as HG.

Communication between new parents and their babies

122. Bliss's 2021 report, *Locked out: the impact of COVID-19 on neonatal care* [**Exhibit JW/17 - INQ000399372**], outlines the requirements which were put in place for parents on neonatal wards to wear PPE at all times. Many parents highlighted concerns about the impact on them and their baby, including bonding, development, and breastfeeding.

123. The concerns expressed by parents to Bliss around the potential impact of facemask wearing on their baby's development are further set out in Bliss' current position statement on Covid-19 and parental involvement (first published in April 2020, updated on 22 April 2022). [**Exhibit JW/20 - INQ000399376**]. In short, face-to face visual engagement is important for babies' developmental outcomes. There is considerable fear that this was impacted by masks. Bliss heard from one unit about the impact on one baby, who was unable to settle after discharge from the unit unless their parents were wearing masks, as they had grown so accustomed to not seeing their parents' faces.

124. Bliss' position statements set out their recommendations for how neonatal settings should support parental presence and involvement in care and decision-making for their babies on neonatal units during the pandemic. The intended audience was neonatal healthcare professionals and NHS and political policy-makers who were involved in deciding restrictions which should be in place on the neonatal unit. Some neonatal professionals found this statement useful for challenging their own local Trust policies. A copy of Bliss's previous position statements has been included for reference to demonstrate the evolution of their position statement. [**Exhibit JW/21 - INQ000399377**]

125. Bliss' most recent April 2022 position statement **[Exhibit JW/20 - INQ000399376]** recommended that parents be able to remove their masks when interacting with and caring for their baby cotside, to support development, and enable bonding and caregiving. This approach was later adopted into the Covid-19 'Frequently Asked Questions' guidance produced by the British Association for Perinatal Medicine (**'BAPM'**) [**Exhibit JW/22 - INQ000399378**]. Various iterations of that Covid-19 guidance were sent out and these are not all available online. However, Bliss' records indicate that the advice on parents removing masks was first recommended by BAPM in or around July 2020.

Communication between parents and healthcare staff

126. While the use of PPE was crucial in helping to keep healthcare professionals safe, Bliss and The EPT identified that the use of PPE, particularly facemasks, did sometimes inhibit communication between parents and healthcare professionals. It therefore presented another

barrier in providing empathic care which had a particular impact when difficult news was being communicated and discussions about care planning were being made. The National Bereavement Care Pathway (**'NBCP'**) Full Guidance Document for Miscarriage, Ectopic Pregnancy, and Molar Pregnancy **[Exhibit JW/23 - INQ000399379]** recognises the importance of non-verbal communication and, in relation to an ultrasound examination, the Guidance Document states:

> *"Staff should be aware that parents are often highly sensitive to non-verbal messages and body language during scans. Parents may become alarmed if the screen is turned away from them or if the sonographer's facial expression and demeanour change or if a colleague is called into the room/consulted in the absence of any explanation."*

> Q43 - *"I couldn't kiss my baby or even smell him or just simply rest my cheek on his head. I felt like I had a lot taken from me having to wear PPE. I understand it was for everyone's safety but still it was awful."*[47]

> Q44 - *"I have never smelled or kissed my own baby, he has never seen my face and might not for months. It's heartbreaking."*[48]

> Q45 - *"[I felt] Cut off from my baby. She's 8 weeks old and I haven't kissed her yet."*[49]

> Q46 - *"In neonatal unit I had to wear a mask. This made breastfeeding very difficult and affected skin on skin. I hated the mask, I'd get hot and struggle to look down at my baby when trying to breastfeed. It made me frustrated and sad."*[50]

> Q47 - *"I felt that it hindered the bonding between myself and husband and our babies and was pointless in the sense that skin to skin and breastfeeding etc. were still very much being encouraged so wearing mask gloves and apron to then put baby on your skin or on breast made little sense to me."*[51]

127. The negative impact on communication between healthcare professionals and patients was magnified for families who had communication difficulties – for example, if they did not speak English as a first language or had hearing difficulties.

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[47] Anon mother of a baby born in May 2020.
[48] Mother to a baby born in October 2020.
[49] Mother of a baby born in November 2020.
[50] Mother of a baby born in July 2020.
[51] Mother of twins born in May 2020.

> *Q48 - "When PPE and social distancing was introduced, we had to learn how to communicate differently. Whereas once we may simply rest a hand on someone's shoulder to say 'I understand how you feel, I am here to support you', we now had to sit 2 metres away when breaking bad news such as diagnoses of miscarriage and ectopic pregnancy, and it felt very impersonal. I found myself constantly apologising that we had to sit further apart and also that we were not allowing partners / support people in.*
>
> *The use of facemasks was challenging as for some people we could no longer read facial expressions, and you may miss small cues that you would otherwise pick up on - has a person really understood? do they need more time to think? do they need more support? Of course, all of these questions could be asked but it didn't feel the same.*
>
> *I worked in an area with a high population of Bengali women, and for those women it was the norm to have their faces covered but when the healthcare professionals had to wear facemasks, this felt like sometimes it exacerbated the language barrier. If a patient was Covid positive and it was not safe to delay their care / investigations, we would have to 'gown up', with masks and visors - I felt that it made patients feel much more scared and isolated and I really empathised with them."*[52]

Impact on pregnant women and people who were experiencing grave sickness

128. For HG sufferers in particular, mask-wearing was very intrusive given that their severe sickness meant that at times they vomited into their masks. This added to the already difficult experience of pregnant women and birthing people struggling through HG. In Pregnancy Sickness Support's view, these experiences have created more mistrust between patient and healthcare professional. Pregnant Sickness Support has been informed by some of those who suffered with HG during the pandemic that they are too anxious and too traumatised to even think about having another baby.

I. Restrictions on visitors in maternity and neonatal care settings.

129. During March 2020, as the pandemic began to intensify, the introduction of access restriction policies was very fluid and often became increasingly restrictive within days as hospitals continued to react and grapple with how to deal with this unprecedented situation. For pregnant women and birthing people, many of whom had been admitted when usual policies were still

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[52] Anon nurse working in the NHS who also assists The EPT.

in place, this was disruptive and difficult to cope with. The PBPOs' view is that the restrictions on visitors in maternity care and neonatal settings was one of the greatest challenges of the Covid-19 pandemic for its members, service-users and recipients of its organisations' support.

General effect of restrictions

130. In the PBPOs' experience, the absence of partners from antenatal checks, scans (sometimes revealing news of pregnancy loss or fetal abnormality) and early labour left women and pregnant people feeling unsupported, abandoned and vulnerable, especially as midwifery staffing levels were sparse. Furthermore, women and birthing people in postnatal wards felt isolated and alone, without any help from their partner to care for their new baby or even to walk to the bathroom.

131. The impact of these restrictions was also egregious for sufferers of severe pregnancy sickness. In Pregnancy Sickness Support's experience, HG sufferers were forced to attend hospital appointments and admissions alone, without any support from friends and family. In many cases, those with severe sickness struggled to even walk to the ward by themselves but had no other choice but to do so.

132. The EPT was informed about partners who saw their loved ones experiencing an ectopic pregnancy and being rushed to hospital alone and who were then left in the dark as to what had happened to them:

> Q49 - *"I was in hospital for 5 days in total. They did bend the rules to allow my husband to see me late on the first night after the surgery (given the last he'd seen of me before this was me repeatedly collapsing and being whisked away in an ambulance, this was a must for his peace of mind). After that, he was only allowed to visit me for 1 hour a day. This was obviously really tough on both of us and never felt like enough for everything we had to process. Furthermore the limit of one visitor a day meant my mum couldn't see me, which was also hard."*[53]

133. During the early weeks and months of the pandemic, Bliss received emails from families asking about access restrictions on their unit and seeking support with challenging them. For many families Bliss spoke to, they felt the restrictions were nonsensical as they did not appear to be contributing to reducing infection risk. For example, it was pointed out that parents would be able to be together at home, in other parts of the hospital (e.g. waiting rooms/corridors) and drive to the unit together but were not allowed to be present together at their baby's cot-side. These policies became particularly difficult to tolerate as wider societal restrictions changed – especially when lockdowns ended, 'eat out to help out' was encouraged, and social distancing

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[53] Anon Lived perspective from a supporter of The EPT.

lessened. It was understandably frustrating and upsetting to families that outside of hospital they could, if they chose to, socialise and live as 'normal' - as could staff caring for their baby – and yet on the unit they were unable to care for their baby together.

> Q50 - "[I felt] alone. I only saw our baby together once for his first bath and not again until discharge. I also felt that because we could only be one at a time, my wife and I rarely spoke to each other during the day while we were there."[54]

> Q51 - ''Not being able to be on the ward together was so hard and definitely had an impact on our ability to gel as a family (as this was our first baby) - I felt bad for my husband for every moment I was on the ward and not him. [It] had [a] major impact on breastfeeding which in turn had an impact on my baby's care and length of stay in hospital.''[55]

> Q52 - "[I felt] Like I wasn't her mum. Like someone else was raising my baby. Like me and her dad weren't important enough to be there. All of the 'firsts' I should have been able to do with my baby were taken away from me."[56]

134. The anger and frustration felt by some parents was palpable. Bliss was contacted by families through its email helpline who were seeking support on how to take legal action against Trusts or raise complaints against hospitals. Many parents also struggled in silence. In the survey of 510 parents which informed Bliss' report, *'Locked out: the impact of COVID-19 on neonatal care' dated 2021* [**Exhibit JW/17 - INQ000399372**] 52% said they found the restrictions difficult, but felt they had been put in place for safety reasons; 14% had complained about restrictions; and a significant minority, 31% did not complain, but did consider it. 7% considered complaining post-discharge, 2% wanted to but didn't know how, and 8% wanted to but were worried that by doing so, it would affect their baby's care.

135. These access restrictions also had a serious impact on parent-infant relationships and caregiving. Again, in Bliss' report*, 'Locked out: the impact of COVID-19 on neonatal services'* dated 2021 [**Exhibit JW/17 - INQ000399372]** this impact was outlined in extensive detail. Relevantly, 61% of parents who responded to the survey said that restrictions on the unit had affected how much they could be with their baby or babies and 41% of the parents surveyed said that going through a neonatal admission during the pandemic restrictions affected their ability to bond with their baby at some point. Parents told Bliss that the restrictions in place on units made them feel that they were not being treated like a parent; that their rights as a parent

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[54] Anon father of a baby born in July 2020.
[55] Anon mother of a baby born December 2020.
[56] Anon mother of a baby born in April 2020.

were being taken away; and that they felt an overwhelming pressure to relay complex medical information accurately to their partner and to be able to answer their questions when they had been the sole recipient of information about their baby's condition.

136. Twins Trust reports that, during the relevant period, the unique needs of parents expecting multiples meant that many of the restrictions imposed during the pandemic impacted them to a particularly significant extent. In April/May 2023, The Trust surveyed 251 people with over 70% saying that having a multiple pregnancy made a difference to their experience of maternity services during Covid-19 [**Exhibit JW/24 - INQ000399380**].

> Q53 - "I feel deprived of my rights as a mother."[57]

137. The majority of multiple pregnancies are considered "high-risk". As a result, women and pregnant people with multiple pregnancies have significantly more scans and hospital appointments than their contemporaries carrying one baby and are subject to more and longer tests throughout. Even women and pregnant people with straightforward multiple pregnancies will be scanned more than 10 times throughout their pregnancy. These scans take longer, often more than an hour, and a routine fortnightly hospital visit can take three hours or more for those with multiple pregnancies. Unfortunately, women and pregnant people with multiple pregnancies also experience more complications and are more likely to hear bad news at some point during their pregnancy.

138. In just under half of twin births and almost all triplet births, at least one baby has to be admitted to a neonatal unit. Multiples tend to be premature / small, so they need extra care at the start of their lives. Many of the families Twins Trust works with reported that only one parent could visit the babies on NICU, meaning that both babies could not be attended to, and the parents did not have each other for support during these extremely difficult visits. As previously mentioned, but repeated here given the importance of the issue, the needs of, and support for, parents with multiples and their babies should have been more carefully considered. The "lessons learned" are addressed below in our final recommendations section.

139. Additionally, the allocated time per NICU visit was the same as for singleton babies, but the time had to be split between two, three or more babies on the unit, meaning that each baby received significantly less attention than normal. People had to decide which baby to prioritise:

> Q54 - *"Only one parent was allowed to visit per day and my twins were in separate incubators on different places in the wards (even at one time on different wards) so I had to split my time between them."*[58]

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[57] Anon mother of a baby born in August 2020.

[58] Anon parent.

140. Twins Trust was approached by people who confirmed that, due to these restrictions, their partners had to make monumental decisions over how to manage visits, particularly if the babies were in different settings (i.e. one at home, the other on NICU, the other on the neonatal unit). The guilt which these traumatised, exhausted families are still contending with is overwhelming:

> Q55 - *"The time limits in place at our hospital were brutal (two hours per day and only one parent allowed in per day) and it affected my whole journey as a new mother from being unable to establish breastfeeding to struggling to bond. It also triggered a deep post-natal depression which took over two years to recover from."*[59]

> Q56 - *"I was on the ICU and the babies were on SCBU. A man in the bay opposite me had Covid (I was at that point in a coma) so they then wouldn't let me meet my children as it would breach Covid protocol as I was put into isolation, despite being nowhere near the man. I met them 13 days later in the car park."*[60]

141. Bliss' Report*, 'Locked out: the impact of COVID-19 on neonatal services'* dated 2021 [**Exhibit JW/17 - INQ000399372]** echoes the findings of Twins Trust in respect of the impact of visiting restrictions on twins and multiples. 28% of neonatal units Bliss spoke to had a policy that prohibited both parents being on the unit at the same time, even for the parents of twins and multiples. On those units, one parent had no choice but to split their time between two or more babies.

Progress towards national access guidance

142. As set out above, parents' access to their newborn babies was severely restricted from March 2020. For too long, there was a lack of clear national guidance on how parents' access should be supported during the pandemic. Bliss released its first position statement for neonatal services on 8 April 2020, calling for services to reinstate usual levels of parent access as soon as possible [**Exhibit JW/21 - INQ000399377**], and did significant work thereafter (as set out below at [18987] and [**Exhibit JW/35 - INQ000399392**]) to lobby for the lessening of these restrictions. The BAPM and Royal College of Paediatrics and Child Health (**'RCPCH'**) released guidance for working within neonatal settings around a similar time, though initially there was limited detail in their guidance on parents' involvement in their new babies' care.

143. A key failing in respect of guidance issued across the UK nations on neonatal services was that these services were considered in line with every other hospital service and were therefore

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[59] Anon mother.

[60] Anon mother of twins .

covered by blanket 'visiting' policies which undermined the parental role in caregiving for their baby. In Bliss's view, no consideration was given to balancing the harm of Covid-19 against the harm to newborn babies of separating them from their parents.

144. In England, Wales, Scotland and Northern Ireland, guidance initially suggested that only one parent or guardian could visit a baby in the neonatal unit. Bliss' position statements summarise how guidance across each of the UK nations changed over time. These summaries can be found in **[Exhibits JW/20 - INQ000399376]** and **[Exhibits JW/21 - INQ000399377]**. Some of the original copies of national specific guidance can no longer be found but we have exhibited Guidance from NHS England (March 2020) **[Exhibit JW/25 - INQ000399381]** and Northern Ireland (April 2020) **[Exhibit JW/26 - INQ000256450** stipulating that only one parent can attend a child in hospital.

145. In July 2020, the Scottish Government issued detailed guidance for maternity and neonatal services which was regularly updated **[Exhibit JW/27 - INQ000320538]**. In issuing this guidance, Scotland was the first of the UK nations to define the circumstances in which maternity services could reduce the level of restriction in place and move back towards usual practice. In Bliss' view, Scotland acted the fastest and produced the most thorough guidance for neonatal services which, importantly, set out clearly the expectations for services as they moved through differing levels of the pandemic. That did not mean there was no inconsistency between individual units, but the overall expectations were clearer and there was a more defined path for services to follow to increase parental and family presence on neonatal wards over time. However, the Scottish guidance still came several months after the start of the relevant period.

146. In England, national guidance from NHSE for managing parent access in neonatal units was not produced until 14 December 2020, *Supporting pregnant women using maternity services during the coronavirus pandemic: Actions for NHS providers, version 1* [**Exhibit JW/28 - INQ000399384**]. Although there was variation between neonatal units within all four nations, Bliss consider the discrepancies felt to its staff and its constituency most prominent in England, largely because this is where most neonatal units are located, and where most babies born needing neonatal care are born. There was a sense that services just a few miles apart and which were part of the same neonatal network could have differing policies and therefore offered babies and families who were relatively local to each other quite a significant difference in care experience.

147. Wales progressed more slowly than either England or Scotland on allowing both parents to be present on the neonatal ward. This policy was not re-introduced until May 2022, making Wales a real outlier in terms of enabling parents to be present with their baby compared to England and Scotland.

148. The lack of guidance, particularly in England, contributed to the significant levels of variation experienced. Parents of newborn babies are not 'visitors', yet this was exactly how they were treated, until guidance was produced suggesting restrictions should be reduced. As set out above, Bliss heard from neonatal units which would only allow parents access for two hours at a time; or would only allow the same parent to attend every day; or would permit both parents to attend, but they could only be present on the unit one at a time, effectively taking turns. In Bliss's experience, this particular policy - which enabled both parents' access, but crucially denied them the opportunity to parent together - was particularly persistent, even into 2022.

149. Despite guidance from Bliss, BAPM and RCPCH calling for unrestricted parent access consistently from the summer of 2020, it was difficult for this to be implemented by neonatal services without central guidance. Bliss was made aware that some services wanted to relax their parent access restrictions, but found it difficult to do so due to opposition from Trust management and Infection, Prevention and Control (**'IPC'**) teams. In one tragic case Bliss was made aware of, a mother was unable to be with her baby until her baby was dying (several days after birth) despite attempts by the unit to facilitate access, as permission could not be obtained from the Trust.

150. In Wales, there was national guidance, *Visitor guidance to in-patient health settings in times of Coronavirus (COVID-19),* published 25 March 2020 **[Exhibit JW/29 - INQ000399385]**, stating that 'v*isiting patients who are not infected with Covid-19 should be permitted for: one parent or guardian for paediatric inpatients and neonates'.* However, it took until May 2022 for the guidance to be updated to advocate unrestricted access to newborn babies for both parents. Bliss met with Welsh Government representatives in Summer and Autumn 2021 and was clear with them that Wales had become an outlier in terms of progress towards enabling parents to be present with their baby. Notwithstanding this, by December 2021, Bliss received confirmation that nearly all neonatal units in Wales were still only allowing parents to be present together for a limited period of time. Welsh Government guidance to promote both parents being present together, unrestricted, was not introduced until May 2022.

151. These experiences are echoed by other PBPOs. Despite the updated NHS England guidance in December 2020, that new mothers and birthing people should not be separated from their partners, many women and birthing people responded to an NCT survey in July 2022 saying that they had found partners' presence discouraged or restricted, e.g.:

> Q57 - "*Dad was sent home… whilst I was still under the influence of the anaesthetic, I could barely hold baby, and midwives were so busy they were unable to help. I just felt useless and so alone.*"[61]

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[61] Anon NCT survey response.

NCT eventually published a summary of NHS guidance to help parents understand the situation: NCT, 'Birth partners and coronavirus' (last updated 2021) [**Exhibit JW/30 - INQ000399387**]

152. It was not until Spring 2021 that NHSE added neonatal parent access to the weekly situation reporting (SitReps) required from Trusts, which meant neonatal access policies were reported to NHSE consistently for the first time. Trusts were asked whether their unit provided 24-hour access for parents to their babies, and were asked to detail whether this was: yes, both at the same time; yes, but restricted to one parent; no, due to Covid-19 restrictions; no, same as pre-pandemic; or N/A. Bliss received information from a contact within NHSE on 1 July 2021, that at that point, 75% of neonatal units in England were allowing both parents access at the same time. Bliss was subsequently updated verbally at regular meetings with NHSE that over subsequent months this steadily increased to around 95% of units in England. It is understood that, currently, parent access in England is back to how it was pre-pandemic.

Inconsistency between services

153. As outlined in the sections above, the restrictions to neonatal services had a significant impact on babies and families. Due to the level of autonomy that local NHS Trusts and Health Boards had when implementing rules around access, there were high levels of variation between services.

154. Bliss was made aware that Trust and Health Board Infection and Prevention Control Teams ("IPC") in particular presented a barrier for units wishing to restore pre-pandemic parent access policies. While the IPC teams were understandably working in extraordinarily difficult circumstances to keep the whole hospital safe, it was extremely challenging for units to change their policies if their IPC teams were unable to balance the potential harm of Covid-19 infection with the harm that was being caused to babies and their families by separation.

155. When the first national guidance in England on parental access in maternity and neonatal settings was released by NHSE in December 2020, Trusts were asked to support a return to parent access by undertaking three activities: conducting risk assessments, changing unit layout and regular testing of parents.

156. Bliss' Locked Out report asked Trusts about their progress towards these three measures between 26 February 2021 and 26 March 2021 **[Exhibit JW/17 - INQ000399372]**. The majority of Trusts (80%) had undertaken risk assessments to identify whether there was a risk of transmission by having both parents present on the unit, and a further 6% were in the process of doing this when Bliss surveyed them. Bliss also asked whether the impact of separation on the baby and family had been looked at and included in the formal assessment. While many units said they had considered this, a substantial minority (35%) had not included this in a formal assessment. Trusts were even less likely to have conducted an equality impact

assessment, with just 28% of units which had completed, or were in the process of completing, a risk assessment having included an equality impact assessment.

157. Similarly, as outlined above in terms of progress towards implementing national guidance in Wales and ensuring units were able to facilitate as much parent access as possible, Health Boards had the autonomy to make decisions. In Bliss's meetings with Welsh Government officials, the officials stated they were unable to make Health Boards enforce the guidance in full. Health Boards similarly had autonomy in Scotland, but Bliss' view is that of, all the national guidance, the Scottish Government's was the most clearly defined and directive regarding how parent and family access should be managed. Indeed, Scotland was the first nation to outline to Health Boards how they could facilitate sibling and wider family access in neonatal settings.

158. Around 15,000 babies will receive care in more than one hospital during their neonatal admission. For parents and families, this means adjusting to a new way of doing things, a new unit culture and new rules. This is challenging enough in usual times but was exacerbated during the pandemic when different hospitals had different rules around access. For example, the first unit may have permitted parents to be present together, only for the baby to be transferred to a different unit for care where parents could only attend separately. For families who experienced this, this contributed negatively to their experience.

159. There was also significant variation in policies governing labour and postnatal wards and paediatric settings and this variation could be within the same hospital. This meant that parents who were able to stay with their baby in one setting were unable to stay with their baby in another. This was particularly difficult for mothers who were receiving inpatient postnatal care, and for families of babies who were discharged to a different paediatric speciality from the neonatal unit.

Particular effect of restrictions on those receiving bad news about their pregnancy

160. In the PBPOs' experience, the restrictions on visitors in early pregnancy and maternity care settings had a particularly negative impact on those receiving bad news about their pregnancy.

161. Of those surveyed by The Miscarriage Association who were given in-person hospital appointments, 77% stated that they were unable to take anyone with them. Fewer than 25% were allowed to make a phone call or video call while the appointment was happening.

162. Of the minority who were allowed someone to attend the appointment with them, 25% of those women and pregnant people were then not allowed to have that person come into the scanning room with them.

163. For many women and pregnant people, this meant having to receive news that their baby had died or had not developed as it should, by themselves, while their partner had to wait alone in the hospital car park. As well as leaving partners feeling helpless and isolated, this meant that

those women and pregnant people who were already suffering with the physical loss also had to absorb complicated information or treatment options while unsupported. Among the many comments received by The Miscarriage Association in its survey were:

> Q58 - *"It was heartbreaking to lose my baby - the only child I conceived in a three-year ongoing infertility journey - confused, masked, distraught and without my partner to hold my hand and grieve with me."*[62]

> Q59 - *"Dealing with miscarriages alone during covid was heart breaking, husband had to sit in the car park whilst I had to be scanned and receiving the sad news (I had multiple miscarriages during the pandemic one of which almost killed me from blood loss) being alone in hospital was horrible just sat staring at blank wall knowing your body is failing you again."*[63]

> Q60 - *"It was one thing being completely alone in hospital when having my miscarriage confirmed and having to decide how to manage things. But knowing that the government were having parties at the same time is disgusting and fills me with so much anger. I remember meeting my husband at the entrance to the hospital to decide on how to manage things, I'll never forget the group of men standing there waiting for their partners come out from appointments and scans. It was so inhumane and a memory I'll never forget."*[64]

> Q61 - *"My husband wasn't allowed with me. It was painful both physically and mentally and he was made to wait in the car park whilst I had several rounds of medical management and lastly the surgery. I shouldn't have had to experience that alone."*[65]

> Q62- *"I had a routine scan which my husband couldn't attend but the reason it affects me now still is because I later lost my baby, she was born at 20 weeks but I had a missed 2nd trimester miscarriage as she passed at 16 weeks. My husband never got to see her alive as he wasn't at that first scan."*[66]

> Q63 - *"Mine was a molar pregnancy. I wasn't allowed my husband in hospital the day I had surgical management and he instead sat outside in the car park all day. When I then had to attend Charing Cross in London to begin chemotherapy my husband*

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[62] Anon The Miscarriage Association survey respondent.
[63] Anon The Miscarriage Association survey respondent.
[64] Anon The Miscarriage Association survey respondent.
[65] Anon The Miscarriage Association survey respondent.
[66] Anon The Miscarriage Association survey respondent.

> *was only allowed in the clinic and when I was moved to the ward he was unable to visit for my week stay."*[67]

164. For The EPT, from setting foot into the hospital for nerve-racking tests alone, to receiving bad news alone, to recovering from treatment alone, all stages of the experience of having an ectopic pregnancy were intensified by the restrictions on visitors in hospitals. The EPT received many lived-experience accounts of the impacts of restrictions on visitors in early pregnancy settings. A range of case studies are set out in detail at **[Exhibit JW/31 - INQ000399388]** but three particular case studies of women's experiences are reproduced here:

> Q64 - *"Once in the hospital, everything happened very quickly after I collapsed on a nurse trying to take blood samples. I was rushed through to a "resus" ward - several doctors about asking me questions and lots of tests going on. I had to sign a few consent forms but I was in so much pain I couldn't really read the details of what I was signing - although they had explained pretty clearly what they needed to do and what they consent forms were for. I do wish my husband could have been there to check what I was signing - although I trusted the doctors looking after me."*[68]

> Q65 - *"I then had to return to the waiting room alone. At that point I was able to ring my husband and he was briefly allowed to be with me as I was prepped for surgery. Although my surgery was an "emergency", I actually ended up being alone in a room for five hours waiting to be the next on the list. My phone battery was dying and I was checked on twice in this time. I just had to lie there alone processing it all as my husband was not allowed to stay with me."*[69]

> Q66 - *"I have not been able to see my husband for more than 12 hours in almost a week. He hadn't understood what is going on (neither have I) and I have been so lucky that my mum knows the system so had been able to advocate for me. This is a difficult enough time for anyone, but it has felt so lonely and confusing. It's hard enough to take in information when you're experiencing a trauma, let alone when on strong painkillers and having to try and make decisions with loved ones who don't have all the information. I had to tell my husband that not only had we lost two babies (our first pregnancy), but that my life was also at risk. He has been worried sick and feels helpless, and had to wait for me to phone him to let me know I had come round*

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[67] Anon The Miscarriage Association survey respondent.

[68] Anon Lived perspective from a supporter of The EPT.

[69] Anon Lived perspective from a supporter of The EPT.

> *and surgery went well. This time is awful for anyone to go through but the emotional toll of being alone, having to tell your partner that your baby will not survive, decide what to do with the embryo's remains alone because there's no phone signal, and not being there to comfort one another is even worse. I feel worse for him because he has been left with the internet as his only real source of information and can't really start grieving yet."*[70]

165. Excluding partners or other support meant that women and pregnant people suffering early pregnancy loss experienced isolation in an extreme way. They endured a confusing and traumatic experience alone with little or no emotional support from loved ones. In addition, not having an additional support person in the room further reduced women and pregnant people's ability to digest complex information about their condition and pregnancy. Furthermore, in The EPT's experience, joint decision-making for sensitive disposal of remains was affected by the restrictions.

166. The EPT has learnt that the family and friends of women and pregnant people now have their own complicated healing journeys to navigate as a result of the restrictions. Having had little exposure to what was happening in clinical settings, some struggle to understand the gravity of what their loved one has been through:

> Q67 - *"There were a few times I broke down into tears whilst in hospital. Whilst the nurses were lovely and did their best to comfort me, all I really wanted was my husband. I think not being in the hospital and seeing everything I was going through has made it harder for him to really understand just how traumatic the pre-surgery emergency bit was for me. I tell him about it a lot and he can see the emotional effect it has had on me, but that's no substitute for actually being there and seeing everything first hand."*[71]

167. In The EPT's view, partners have been left adrift with even less or no support, despite having also experienced traumatic events.

> Q68 - *"I also wish my husband could have been there at the moment they confirmed I was pregnant - we didn't know before this and I'm sad he missed out on that. To him, it still doesn't feel "real" that there was a foetus there. After the surgery, they handed me another consent form to cremate the foetus. Again, I wish my husband and I could have done this together."*[72]

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[70] Anon Lived perspective from a supporter of The EPT.
[71] Anon Lived perspective from a supporter of The EPT.
[72] Anon Lived perspective from a supporter of The EPT.

168. For the families of multiples, where the risk of receiving bad news is statistically higher, the restrictions imposed during the pandemic affected them significantly, as they had to receive this news alone, without their key familial support network at such a critical and traumatic moment. Twins Trust was told about many such experiences:

> Q69 - *"I had to find out one of my twins had a life-threatening heart defect at a scan on my own."*[73]

Care and access to services for bereaved families

169. Most critically, disruption of services coupled with wider societal restrictions and access restrictions on maternity units meant parents experiencing the most difficult time of their lives had to do this alone, without the support of their families.

170. Bliss' Locked out study in 2021 **[Exhibit JW/17 - INQ000399372]** found that, in respect of neonatal units, all 70 neonatal units who responded to the survey, (Bliss sent the survey to 161 units and 70 responded) said they would flex their parent access policy if a baby was critically ill or receiving end of life care, even if their policy did not currently allow parents to have full access together. However, the extent to which these policies were in fact altered by units in these situations is variable. It ranged from full family involvement (including siblings and wider family) to small flexibilities, such as parents being able to be present more than once per day. These policies also did not account for the fact that, when a baby is critically ill or receiving palliative care, some babies will decline very quickly, and sometimes unexpectedly. Parents may have missed out on days or weeks or more of being with their baby regularly before their baby tragically died.

> Q70 - *"[There was] no access for family members except when death was imminently expected and then it was only one at a time."*[74]

> Q71 - *"Our oldest son was never allowed in to see our baby even though this was requested on multiple occasions. Our son was asking to see him and we felt this was the only thing that would help him and offer some understanding."*[75]

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[73] Anon mother of twins.

[74] Father of a baby born in October 2020, who died in neonatal care.

[75] Mother of a baby born in July 2020, who died in neonatal care.

III. PBPOs' ROLE FILLING THE GAPS LEFT IN ACCESS TO EARLY PREGNANCY, MATERNITY CARE OR NEONATAL SERVICES

171. Of the PBPOs which provide help and support to families, many felt that there was an extra drain on their resources due to gaps in access to mainstream early pregnancy, maternity or neonatal care and services, and that they needed to be available to provide more support than usual.

172. Aching Arms found that parents turned to the charitable sector to fill the gaps otherwise addressed by specialist midwives both in hospitals and in the community. Therefore, the charity set out to find other means of supporting bereaved parents through this time whose grief was heightened by the pandemic stay at home guidelines.

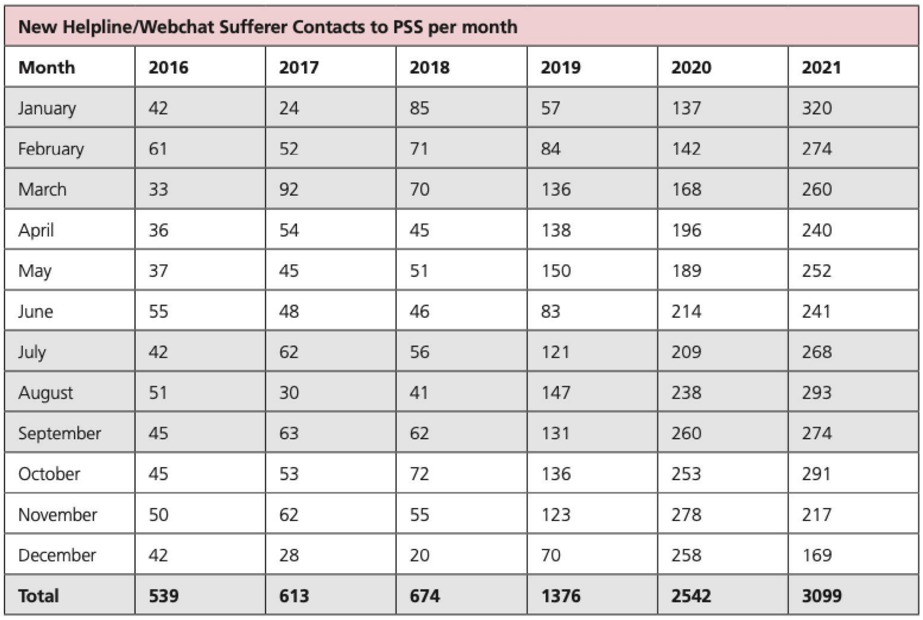
173. A key service Aching Arms usually provides is sending out 'comfort bears' to families who experience baby loss. This had to cease during the Covid-19 pandemic, because of the stay-at-home order, the need to protect volunteers, and restrictions on what hospitals would receive. Instead, Aching Arms set up a support service offering telephone and text support. The aim of this service was not only to fill the gap in support the charity noticed within the NHS, but it also wanted to relieve some pressure on frontline NHS services by extending its service and providing support to bereaved families.

174. During the relevant period, The Miscarriage Association also saw demand for its services increase significantly. Calls to the Association's helpline and other direct contacts increased by 37% in the first three months of the pandemic and continued to be at higher than usual levels across the next two years. The Miscarriage Association made immediate changes to its website to create a Covid-19 information hub, with links to official guidance and information, together with its own knowledge and understanding of how the pandemic was impacting access to early pregnancy, maternity care and services.

175. In the Pelvic Partnership's experience, as in-person services shut down, women and pregnant people with PGP were forced online to access support, information and treatment for their condition. That was documented in an online survey by The Pelvic Partnership exploring women's experiences of pregnancy-related pelvic girdle pain (PGP) within the last 2 years, conducted from March-April 2022 **[Exhibit JW/32 - INQ000399389]**. In 2020/2021, the charity experienced a 150% increase in demand for its support services (via a helpline and online through social media), and continued steady growth in 2021/2022. The Pelvic Partnership had particular requests for support from women and pregnant people asking how they could manage their pain without access to manual therapy. The Partnership therefore updated its social media pages and began sharing crucial information such as: plain English summaries of the key guidance from the RCM, Royal College of Gynaecologists and other professionals organisations; practical suggestions on how to manage pain without access to manual therapy, later collated into a free e-book released in 2021, 'PGP is treatable!' (see *The Pelvic*

Partnership, PGP is treatable, Pregnancy-Related Pelvic Girdle Pain, First Published March 2021 **[Exhibit JW/33 - INQ000399390]**); and other reassuring and supportive content.

176. Pregnancy Sickness Support similarly observed a rise in the number of contacts to its helpline and webchat service. Both methods of contact showed month-on-month increases from 2019, and almost quadruple the number of contacts from 2018. By the end of August 2020, the total number of contacts from sufferers had exceeded the number of contacts for the whole of 2019. This trend was maintained throughout 2020 and 2021, as seen in the table below. This table is taken from a Pregnancy Sickness Support National Lottery Grant Fund application, and is not exhibited in full for reasons of commercial sensitivity and irrelevance.



New Helpline/Webchat Sufferer Contacts to PSS per month

Month	2016	2017	2018	2019	2020	2021
January	42	24	85	57	137	320
February	61	52	71	84	142	274
March	33	92	70	136	168	260
April	36	54	45	138	196	240
May	37	45	51	150	189	252
June	55	48	46	83	214	241
July	42	62	56	121	209	268
August	51	30	41	147	238	293
September	45	63	62	131	260	274
October	45	53	72	136	253	291
November	50	62	55	123	278	217
December	42	28	20	70	258	169
Total	**539**	**613**	**674**	**1376**	**2542**	**3099**

177. NCT also provided significant support to new parents who were seriously affected by isolation from family, friends and direct contact with health professionals during the relevant period.

178. In particular, NCT transformed its in-person antenatal and other courses into online courses. Between 22 March 2020 and 28 June 2022, the organisation offered 12,928 online courses and workshops. These received positive feedback from attendees including those emphasising the benefit of learning from NCT and meeting other families despite the lockdown.

179. NCT also put immense efforts into organising ‘Walk & Talk’ (**‘W&T’**) groups to address the distress caused to new parents by the restrictions imposed that prevented them meeting and talking to other parents in the neighbourhood. Working within restrictions and government exemptions (as the walks offered therapeutic support), NCT volunteers led local walks for parents enabling them to make contact, chat and discuss their experiences. W&Ts were extremely popular. Between September 2020 - when the W&T programme was first introduced - and June 2022 volunteers organised and hosted 7,790 W&Ts and 54,560 parents across the

UK attended them. Some parents described these as the only event in a week they could look forward to:

> Q72 - *"I can't put into words the difference and impact these walks had on my mental health. As a first time mum having my son at the beginning of the pandemic, I'd had many struggles. Simply having an hour of time with other parents outside was amazing and a real lifeline"*[76]

180. Mothers at home with new babies often need support with breastfeeding. Pre-pandemic, this support was available face-to-face either via NCT or NHS services. NCT moved its Breastfeeding and Infant Feeding drop-ins online during lockdown and offered virtual support via Zoom/Skype/Facetime/Facebook messaging/Phone. Senior NCT staff reported anecdotally that, in some areas, NCT was the only infant feeding support provision due to NHS staff being re-deployed.

181. The Lullaby Trust identified the biggest gap in services as the lack of patient access to maternity health professionals who (particularly in the first lockdown) were deployed to other areas of the health service. Appointments with midwives, health visitors and other health professionals were limited or were delivered virtually, resulting in fewer opportunities to flag important risk factors relating to safer sleep. Consequently, more families turned to The Lullaby Trust directly to find this information and to ask questions, as reflected in the following helpline data:

    (a) Safer sleep enquiries in 2020 increased by 51%, compared to 2019;

    (b) During the second lockdown (November-December 2020), enquiries grew by 132%, compared to the same period in 2019;

    (c) During the third lockdown (January-March 2021), enquiries increased by 59%, compared to the same period in 2020.

182. As noted above, The Lullaby Trust's national CONI team of qualified health visitors also helped with local shortages by providing direct support to families by telephone and email. CONI resources (such as information leaflets, weight charts and symptom diaries) were sent directly by post and email from The Lullaby Trust to families. It is also usual for the NHS/local authorities to loan donated baby movement monitors and weighing scales and then to distribute to CONI families. During the pandemic this process changed and the donated monitors/scales were sent directly to families as health professionals were unable to carry out visits or unable to access their equipment stores, for example. The Lullaby Trust provided the monitors during the Covid – 19 pandemic and still do.

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[76] 'Cassandra', a parent from Manchester.

183. In the past The Lullaby Trust funded monitors which were multi-use and the NHS then owned and maintained them. There was no capacity to check equipment during the Covid-19 pandemic as those teams were focused on ventilators predominantly so The Lullaby Trust began sending single use monitors directly to families. Some of that change had begun before the start of the Covid—19 pandemic but the pandemic definitely accelerated that change. The national CONI team at The Lullaby Trust also sent links to online training videos on basic life support, in the absence of face-to-face training. Additionally, five short 'bitesize' information presentations about CONI were developed and made available on The Lullaby Trust website. These could be accessed directly by families and health visitors, supplementing their reduced contact with families at this time. The Lullaby Trust also provided one-to-one support to health visitors by phone and email, helping them to reach families remotely instead of by home visits, and created online training modules for health visitors.

184. In the second and third lockdowns, support for families was still limited. Calls to The Lullaby Trust's helpline for safer sleep information were longer and parents asked many questions, rather than calling for a one topic enquiry as the charity had experienced prior to the pandemic.

185. During the relevant period, The Lullaby Trust also saw an increase in the number of parents and carers contacting them for bereavement support, reporting high levels of anxiety. This prompted the charity's Support and Information team to reach out to families on The Lullaby Trust Facebook bereavement support group to ask them how they were coping with the pandemic and how it had impacted on their grief. The Lullaby Trust collated the comments, advice and information obtained via the group in a web page covering bereavement in the pandemic. The Lullaby Trust also introduced a Webchat service in September 2020. This enabled bereaved families to access one-to-one support without having to schedule a phone call. It ensured accessibility of the bereavement support service to families during social distancing measures and was especially helpful to those families who struggled to find sufficient privacy at home for a call by phone. As per the Sudden Unexpected Death in Infancy Bereavement Care Pathway (see *National Bereavement Care Pathway for pregnancy and baby loss, Full Guidance Document Sudden Unexpected Death in Infancy (SUDI) up to 12 months, for use in England from July 2022.* [**Exhibit JW/34 - INQ000399391**]), it is important that families have access to professionals to support them in their bereavement, such as specialist bereavement midwives, so redeployment of these highly specialised roles can be avoided in future pandemics.

186. The EPT was able to fill gaps in early pregnancy, maternity care and services by providing general information and support across people's experiences of ectopic pregnancy, from identifying symptoms to trying to conceive again. These services had already been provided remotely for a number of years so The EPT's resources remained mainly available, with some

adaptations to reflect staff and their family members being at home during lockdowns. The EPT filled in gaps in access to early pregnancy care or services by taking the following steps:

(a) liaising with medical advisers to obtain the most up-to-date information on the impact of restrictions on early pregnancy care, including rationalisation of services, and sharing this on The EPT's website/social media channels;

(b) responding to questions received from the public on e.g. whether they needed to self-isolate after treatment and liaising with medical advisers to find the answers;

(c) creating a dedicated website area about ectopic pregnancy and Covid-19 with common questions and answers, including regularly updated links to guidelines;

(d) encouraging (especially via social media) symptomatic women and pregnant people to seek medical assistance, particularly during lockdowns;

(e) providing information on what to expect during diagnosis, treatment, and recovery which was particularly crucial given healthcare professionals' time and resources were stretched beyond expectation and women and pregnant people were having to attend scans/appointments alone; and

(f) providing safe spaces for people to express themselves, in the absence of usual support systems like visits from family and friends. The support team worked increasingly flexibly to keep up with demand and noticed increased levels of need and isolation.

187. Other PBPOs with a focus on national and local advocacy focused on providing information on gaps in access to maternity care and services and explaining Government policy to new parents. For example, Bliss mobilised quickly to:

(a) Create a position statement on parent access to babies in neonatal care and involvement in that care, in response to the severe restrictions which were imposed (addressed in detail above). The first version of this was published on 8 April 2020, and it was updated five times, with the final version published on 22 April 2022. This proved to be influential for informing practice at local and regional level, as well as (more slowly) national level. The statement also informed Scottish Government Guidance, BAPM & RCPCH guidance; and ultimately the development of NHSE guidance.

(b) Provide regularly updated information to parents about what wider Covid-19 restrictions meant for them and their babies. Bliss also provided information to parents with a baby or child at home who was shielding. In the first couple of months, this meant updates as often as several times a week.

(c) Develop an online support service to provide access to a trained volunteer via video link.

(d) Develop a video to be hosted on the vCreate platform which signposted parents to Bliss and shared opportunities for how to be involved in their baby's care, even if they could not be present on the unit as much as they wanted to be.

(e) Support neonatal staff who were keen to see parent access returned to usual levels, or at least to ease some level of restriction. Many were struggling to secure sign-off on this from IPC teams & Trust management. To support their case, Bliss wrote letters of support to a number of Trusts where staff felt this input would be helpful.

(f) Send a weekly email update to its healthcare professional subscribers and ad hoc signposting and support for neonatal units.

188. Twins Trust moved all their antenatal sessions online so parents of multiples were still accessing the vital information they needed. There were Covid-specific pages on the website which listed all the support and changes in help. This included the latest information from the RCOG on the vaccine for pregnant women and birthing people. They set up a text information service to distribute their support and resources and extended their crisis service to support new mothers in hospital, just home from hospital and anyone else who had lost their support network and gave them remote help including introducing virtual clubs to bring people together. Twins Trust provided free 'Practical Preparing for Parenthood' and breastfeeding courses and provided webinars on home schooling and challenging behaviour focusing on the challenges faced by parents of multiples.

IV. COMMUNICATIONS OR SUBMISSIONS MADE BY THE PBPOs TO GOVERNMENT / NHS BODIES REGARDING THE PROVISION OF EARLY PREGNANCY, MATERNITY AND NEONATAL CARE OR SERVICES

189. Bliss, The Lullaby Trust, and the Pelvic Partnership all made submissions or had relevant communications during this period. A full list and the submissions can be found at **[Exhibit JW/35 - INQ000399392]**. Bliss in particular made an extensive number of national submissions during the relevant period, as well as lobbying and advocacy communications and submissions with local NHS bodies.

190. Other, smaller organisations like Pregnancy Sickness Support did not have the capacity and were therefore not in a position to communicate their front-line experience to officials.

191. Further, other groups like the NCT expressed their position verbally or through other informal communications and collaboration rather than formal submissions. For example, NCT is represented on the Medicines & Healthcare Products Regulation Agency's consortium for Safer Medicines in Pregnancy & Breastfeeding. In 2021, as the Covid-19 vaccines began to be rolled out, the NCT representative verbally requested clarity on the safety of vaccination in

pregnancy and breastfeeding during a meeting of the consortium. Similarly, NCT requested (directly to relevant Trusts) that its services return to NHS postnatal hospital wards to offer breastfeeding support.[77] It also worked with NHS England and PHE to support accurate messaging to the public and particularly to those pregnant. There was a series of meetings between the organisations resulting in several joint social media events: these were detailed in website posts, such as 'NCT hosts expert panel to consider the Covid-19 vaccine, pregnancy and breastfeeding' (10 June 2021) [**Exhibit JW/36 - INQ000399393**].

V. LONG-TERM EFFECTS OF COVID-19 ON THE DELIVERY OF EARLY PREGNANCY, MATERNITY AND NEONATAL CARE

192. Many of the organisations in the PBPOs have identified serious concerns about the long-term effects of the Covid-19 pandemic on how maternity care is delivered. Many of the new ways of working, particularly online services rather than face-to-face care, have now become embedded ways of working. Baby Lifeline's report: "Mind the Gap 2021", showed that, although training is a central recommendation for improving safety in maternity services, gaps which already existed in training due to chronic underfunding and staff shortages became worse during the pandemic. The report gave recommendations to improve training nationally and locally. The Covid-19 pandemic was the most frequently identified barrier to accessing and attending training by respondent NHS trusts, in part due to lack of spaces to attend training in a socially distanced way and because of venues being used as vaccination centres, as set out in the Baby Lifeline report, 'Mind the Gap: An Investigation into Maternity Training for Frontline Professionals Across the UK, 2020/21' [**Exhibit JW/5 - INQ000399402**].

Changes during the pandemic which have become "the new normal"

193. There are some obvious examples of changes introduced during the pandemic which have now become 'baked in'. All NHS physiotherapy face-to-face appointments were ceased in March 2020, with some services adopting a telephone or video triage system instead. The Pelvic Partnership in particular is very concerned that such face-to-face treatment, including manual therapy has not resumed in many areas, and is still not back to pre-pandemic levels of access and activity. Instead, too many women and pregnant people are only offered video physiotherapy, generic exercises and advice. The Pelvic Partnership has had an increasing number of contacts from women and pregnant people who could not afford private manual therapy asking about treatment options. This highlights an inequity in access to healthcare for women and pregnant people who are unable to pay for private treatment and who subsequently have not made the full recovery they might otherwise have expected.

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[77] These requests were local and informal so copies have not been retained.

194. Other organisations have also identified patterns of Covid-19 behaviours which are now the status quo. In NCT's experience, although many face-to-face services have been restored, remote access for maternity care appointments remains a common alternative. This has been frequently debated as a possible benefit for those less able to travel and a more efficient use of midwifery time. However, women and pregnant people report the disadvantage of being unable to build the same sort of relationship with their midwife as was possible before the pandemic. Additionally, it is clear that women and pregnant people in poorer socio-economic circumstances may not have their own devices nor a space for privacy to ensure an appropriate setting for care.

195. For Bliss, certain changes to care are now also entrenched. Mask-wearing, for example, was never the norm in UK neonatal units but some units are keen to retain these in clinical areas (not at cotside) permanently for staff and families. Bliss considers this results in a potential impact on communication between staff/parents in non-cotside interactions. In addition, progress on Family Integrated Care and Family Centred Care for neonatal services has stalled significantly – and even gone backwards – because of the pandemic. Bliss has heard from staff in neonatal services that, if there is an outbreak of Covid-19, wider family access is the first thing to be denied. From conversations with health professionals, Bliss believes that there have been changes in wider attitudes towards parents being involved in care. While the pandemic experience has made some staff in neonatal units keen to accelerate Family Integrated Care work, for others the reduced footfall on the unit had perceived benefits for the working environment.

196. There are also still ongoing issues with access to the neonatal unit. Bliss was made aware recently (in April 2023) that some units are still testing asymptomatic parents for Covid-19, and those who test positive are required not attend the unit for up to 10 days, despite national guidance outlining that asymptomatic testing should *not* be taking place: see *Living with Covid-19: Supporting pregnant women using maternity services and access for parents of babies in neonatal units: action for NHS Trusts, Version 2, 16 June 2022.* **[Exhibit JW/37 - INQ000330938** The guidance states at page 2, para 2(iii) that: "Providers should no longer expect evidence of a negative test before allowing access to maternity or neonatal units. However, if a support person or parent of a baby on the neonatal unit has received a test, and is positive, they should be advised not to attend." Not only does the apparently unilateral failure to follow national guidance impact babies' care and the wellbeing of their parents, but this is also inconsistent with other services, such as the post-natal ward, where (in Bliss's experience) asymptomatic parents are not tested. The situation for wider family members, such as sibling and grandparents, remains patchy. As recently as April 2023, Bliss was contacted by a unit in England looking for the charity's support to help to persuade the local Trust that siblings should be able to attend the neonatal unit. Furthermore, Bliss have learnt through speaking with

neonatal staff[78] in May 2023 that sibling and grandparent access is still not being allowed in neonatal units across Northern Ireland because of ongoing Covid-19 restrictions.

197. It is important that parents can introduce their new baby to other family members and friends, in their time on the neonatal unit. This promotes family bonding, but also provides essential support for parents. This support can be even more important for younger parents, who have told Bliss that their own parents play a vital role in their baby's neonatal care. Furthermore, parents with older children at home have reported to Bliss that a key barrier to them being present on the neonatal unit and involved in their baby's care is the lack of facilities for siblings on units. Bliss strongly recommends that all lingering restrictions on family members' access to neonatal units be removed.

Wider impacts on healthcare services

198. On a broader level, there is concern from some of the PBPOs that, since the crisis period of the pandemic, among some pregnant and postnatal women and people there is a reticence to contact healthcare practitioners because they do not want to *"bother them"* with questions and concerns about their health and wellbeing. Unfortunately, this means that women and pregnant people may not be reaching out about healthcare concerns as soon as symptoms start, only seeking help when symptoms worsen, which can make the condition harder to treat due to increased severity and may delay recovery times.

199. In parallel, there is concern from some of the PBPOs about the strain and stretch of NHS staffing across all four nations of the UK post-pandemic. Repeated RCM reports make clear how the midwifery workforce has been impacted, and similar problems are apparent in obstetrics, anaesthetics and sonography. For example, an RCM press release, *Royal College of Midwives, England state of maternity services 2023 published July 2023,* [**Exhibit JW/38 - INQ000399395**] states: "*The RCM's latest calculation is that England is short of 2,500 midwives. That has a real impact. It leaves existing staff exhausted and burnt out; for many, it pushes them out of the door.*" The *Royal College of Midwives, Wales state of maternity services 2023 report published June 2023* [**Exhibit JW/39 - INQ000399396**] states that Wales has seen: "*a worrying decline in the numbers of experienced midwives. When these midwives leave they take their knowledge and experience, which we need to help train the next generation of midwives, with them…services are currently coping only because of the superhuman efforts of their staff*". The *Royal College of Midwives, Northern Ireland state of maternity services 2023 report published May 2023* **[Exhibit JW/40 - INQ000399398]** also details similar issues: While not all of those leaving the professions have done so directly

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[78] Anon staff member neonatal nurse based in Northern Ireland.

because of Covid-19, it is clear that the stresses of work during that time have led to large numbers reviewing their commitment to the jobs.

200. In September 2022, NHS England sent to all Trusts a letter, *'Midwifery continuity of carer' (21 September 2022)* [**Exhibit JW/41 - INQ000399399**], setting out *"essential and immediate changes to the national maternity programme in the light of the continued workforce challenges that maternity services face."* The letter acknowledged that, *"over the past two years staff have had to work in ways that they never imagined, in difficult circumstances and we know that maternity services are experiencing stress and strain"*. It also confirmed that: "*There will no longer be a target date for services to deliver Midwifery Continuity of Carer*" (a model of care with the *"vision that women should have consistent, safe and personalised maternity care, before, during and after the birth")*. In spite of substantial evidence of the benefits of this model and NHS acknowledgement in its letter that this model of care *"can improve the outcomes for most women and babies and especially women of Black, Asian and mixed ethnicity and those living in the most deprived neighbourhoods"*, these targets have not been reinstated, seemingly due to inappropriate staffing levels in the midwifery workforce.

201. Overall, as a direct result of the pandemic, it appears that the choices for women, pregnant people and their partners appear to be dramatically reduced in the current service, with options for different settings and different approaches to birth far less available.

Positive effects

202. In The EPT's view, telephone triage system with scheduled appointments appears to be safe although a more detailed service delivery evaluation is required.

203. Similarly, Bliss has observed that the remote video diary service vCreate continues to be used by many neonatal units. There are many reasons other than Covid-19 which prevent parents from being with their baby on the neonatal unit as much as they would like to be, which may be why vCreate and other video platforms have remained popular post-pandemic.

VI. INEQUALITY RELATED ISSUES IN THE DELIVERY OF EARLY PREGNANCY, MATERNITY CARE AND NEONATAL SERVICES DURING THE PANDEMIC.

Inequitable impact on babies

204. Parental involvement in their baby's care is proven to be best for babies' developmental outcomes. Evidence shows that long periods of direct care leads to increased weight-gain and improved breastfeeding rates, and skin-to-skin care has been linked to improved long-term development.

205. The sickest babies are likely to have the longest hospital admissions and these babies will have been most affected by the lack of parental and family input into their care during the

pandemic. Some of these babies will have spent weeks or months of their admission with infrequent contact with at least one of their parents.

206. Additionally, babies with parents who were affected by any of the below areas of inequality will have experienced an impact to their care as they are more likely to have spent prolonged periods of time without their parents or family members present, compared to babies who had wealthier parents, or parents who did not have communication needs.

Disability

207. As outlined above, the requirement to wear masks at all times made communication extremely difficult, particularly for those parents who have hearing impairment disabilities. This will have made it much more difficult to be fully involved in decision-making for their baby, and fully informed about their baby's care needs.

Sex and gender

208. When the strictest restrictions were in place in the early weeks and months of the pandemic, these could actively discriminate against dads and non-birthing parents. We are aware of policies where only the birthing parent was able to attend the neonatal unit, for example. Similarly, where parents could choose which parent attended, but were unable to swap, the person who attended was often the birthing parent by default, particularly if they were trying to establish breastfeeding.

Financial

209. There were also examples of financial inequities in accessing treatment. For example, given the limited access to hands-on treatment for PGP on the NHS, many women and pregnant people are forced to consider private treatment. Given the high cost per session (£50-80) it can be financially out of reach for many, who are forced to stay in pain due to inconsistent access to appropriate treatment on the NHS.

210. Many families already find it difficult to attend the neonatal unit as much as they want to due to the increased costs associated with a neonatal admission, coupled usually with a drop in family income as a result of parental leave. This was worse during the pandemic, particularly when lockdowns were in place. Parents reliant on public transport were encouraged to take taxis which were not always reimbursed. As outlined above, closure of onsite facilities also made it more difficult for families to stay close to the unit or eat and drink cheaply when attending their baby. Lower income families were most impacted by these restrictions.

> Q73 - *"We partly rely on benefits at present therefore travel costs were difficult to meet, it meant that I was without food during most of my visits."*[79]

> Q74 - *"We would skip meals to be careful with money and ensure we was with our son as much as possible."*[80]

Digital poverty

211. Bliss and NCT observed that the move to interactive online services, and online methods to keep parents informed when they could not be present on the unit (e.g. during ward rounds, or to share updates through vCreate or similar) or for appointments post-discharge, excluded those experiencing digital poverty. This includes those who do not have access to appropriate devices, and those who have limited access to data.

English not being a first language

212. Parents who do not speak English, or who do not speak English as a first language are also likely to have found it much more difficult to be involved in their baby's care. As above, mask wearing will have exacerbated communication challenges and made remote communication more difficult – particularly if written updates could only be provided in English.

Ethnicity and Race

213. In general, the PBPOs are aware that the MBRRACE collaboration (responsible for confidential enquiries into maternal and perinatal deaths) has reported in its report entitled 'Maternal mortality 2019-21' (Oxford: National Perinatal Epidemiology Unit, University of Oxford) that, "*Covid-19 was the leading cause of maternal death in the UK in 2019-2021 during or up to six weeks after the end of pregnancy…. There remains an almost four-fold difference in maternal mortality rates amongst women from Black ethnic backgrounds and an almost two-fold difference amongst women from Asian ethnic backgrounds compared to white women. These disparities are statistically unchanged from 2018-2020. Women living in the most deprived areas have a maternal mortality rate more than twice as high as women living in the least deprived areas.*" **[Exhibit JW/42 - INQ000399400].** In short, the majority of women who died from COVID-19 in 2020 and 2021 were from ethnic minority groups.

214. One systematic review, entitled '*Overcoming COVID-19 vaccine hesitancy among ethnic minorities: A systemic review of UK studies' by Basharat Hussain et al, dated 31 May 2022* [**Exhibit JW/43 - INQ000399401**] published in 2022 found that *"[Covid] vaccine hesitancy is*

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[79] Mother of twins born in August 2020.
[80] Father of a baby born in December 2020.

associated with ethnicity along with other factors such as younger age, female gender, and lower income". In specifically investigating pregnant women's views on the vaccine, the review concluded that "*compared to women from White ethnic groups, women from ethnic minorities were twice as likely to reject a vaccine*" and there was "*evidence of reduced vaccine uptake in younger pregnant women, women with high levels of deprivation, and women of Afro-Caribbean or Asian ethnicity compared with women of White ethnicity*."

VII. LESSONS LEARNED BY PBPOs ON THE PROVISION OF EARLY PREGNANCY, MATERNITY CARE AND NEONATAL SERVICES DURING THE COVID-19 PANDEMIC

215. Understandably, many of the PBPOs' experiences and learning are specific to their organisation. To the extent they are, these are set out below. However, some general learning is more widely applicable. Below are some preliminary conclusions on learning, however the PBPOs intend to expand upon these points during Module 3 of the Inquiry.

Prioritisation of parents and young children

216. A key learning point is that, in any future pandemic scenario, babies, parents and families of young children must be thought about as a specific group and properly prioritised.

217. As has been repeatedly emphasised throughout this statement, the visitor limits imposed on hospital and care settings were extremely damaging to pregnant women and birthing people and their families. Each member of the PBPOs emphasises the need for greater thought about these restrictions and the need to ensure partners/support persons are not excluded from scans, appointments, birth and after-birth care and to be a part of relevant decision-making.

218. The Miscarriage Association emphasises that provision for access should have included and should include:

    a. Clear recognition that partners can be equally affected by pregnancy loss;

    b. Provision of adequate PPE to minimise infection risks and to enable partners/support to attend appointments;

    c. Where that is not possible, allowing and providing/supporting the use of video calls.

219. Bliss emphasises the need to prioritise and protect parent access to their baby and involvement in their neonatal care in any future pandemic. The policies which were implemented may have been well-intentioned, but they caused harm. Parents were treated as visitors as part of blanket guidance, which was unsuitable for this setting and failed to recognise that, even when a baby is unwell, their parents are still the primary caregivers and must be involved in care and decision-making. There was significant inconsistency in how policies were applied, and how quickly they reverted back to usual practice.

220. In Bliss's view, there must be a clearer framework for more nuanced decision making within IPC teams, supported by training so that all levels of decision-maker understand the role of parents in neonatal care. There was a lack of awareness at executive level as well as within IPC teams about what exactly neonatal services were and why parents should be treated as distinct from visitors. The IPC approach to risk assessment needed to objectively assess the risks and potential harms of all actions being considered. There should have been a framework through which to balance risks and harms of each policy against each other to inform final decisions. If there was not already such a framework, a pandemic preparedness strategy should have provided for the responsive development of such a plan once the issue quickly emerged (not least because of groups like Bliss' advocacy). That would have prevented minimisation of Covid transmission risk being pursued with no consideration being given to the real and lasting harm which separation of babies from their parents could cause, as well as the impact on psychological wellbeing and babies' development.

221. Aching Arms emphasise that bereavement care services for parents should be protected from disruption as much as possible. Alternative methods of providing support for bereaved parents should have been implemented.

222. The Twins Trust consider that the decision-makers needed to appreciate just how important the familial (and beyond) support network is at all times. In particular, there needed to be proper attention and thought given to allowing both parents to attend all hospital visits at the same time, especially where families have a child or multiple children on the neonatal ward. That support is a critical part of mitigating the emotional and practical concerns that necessarily arise in those circumstances. The Trust consider it is clear, from the material set out above, that it is best for the babies and their families to keep them in the same hospital setting where possible, subject to there being specific NICU specialisms and protocols.

223. The Pelvic Partnership feel pregnant women, birthing people and their babies seem to have been de-prioritised during the government response. PGP as an issue is not well-understood by many healthcare professionals who believe that, because it only impacts the pregnant woman or person and not the baby, it is not a priority. This is not the case, as anything which impacts the pregnant woman or person will also impact their unborn baby, and the physical and mental impact of long-term pain needs to be taken into account.

224. In NCT's view, children and families should have been factored in when deciding how many people could meet together. Initially in England, Wales and Northern Ireland, babies/children of all ages had to be included in the numbers. This had a very real impact on new parents and those with young children as it significantly limited the number of people they could meet. It was even worse for those with twins or multiples. Scotland took a better approach from the start and excluded children under 12 from the restriction on numbers. The introduction of support bubbles was also a really important development for many families.

225. Similarly, the Pelvic Partnership express concern that pregnant women and birthing people and their families were not considered priorities for ongoing treatment. PP consider it was not acceptable to withdraw treatment which was previously available (and not to reinstate it) and believe women and birthing people and their families deserved equal prioritisation to people with other pain conditions.

Communication between government and the public

226. Many organisations expressed the need for clearer communication between the Government and specific groups. The failures in communications otherwise led to confusion and misunderstandings in service delivery. This was an area where members of the PBPOs stepped up to ensure members and service-users had enough knowledge of the rules and latest guidance.

227. At the start of the pandemic, the Pelvic Partnership found it very hard to get access to up to date information on the situation facing pregnant women and birthing people and what it would mean for their service users. They monitored the RCM and the RCOG guidance closely and joined their weekly tweetchats on Twitter to get a better understanding of the nuance of the guidance and what it would mean in practice. They then updated their own Covid-19 guidance and FAQs on their website accordingly and shared via their Facebook support group with their service users who were desperate for updates.

228. As Bliss notes, the lack of consistency, and frequent changing of guidance was very difficult for families to manage, particularly if they experienced transfer between hospitals. First, there was a delay in issuing centralised guidance specific for managing parent access policies on neonatal units. This allowed inconsistency and poor practice to become embedded. National governments moved incredibly slowly in terms of setting out expectations of parent access to neonatal units; in England, where the majority of UK babies receive neonatal care, it took 9 months for NHSE to issue its first explicit guidance setting out expectations of parent access in maternity and neonatal settings.

229. Second, Bliss note that even when guidance became available centrally, it lacked the teeth to enforce its recommendations. There appeared to be very little that NHSE or the devolved governments could do to compel individual Trusts and Health Boards to open up access policies, even once they had become clear outliers. Decisions about changing parent access policies were often made at executive level with IPC team input. Bliss know that individual neonatal teams were often proactive about challenging their unit policies and pushed for increased flexibility, but could find it challenging to get this agreed at a higher level. Again, this was also not assisted by lack of clear centralised IPC guidance.

230. Bliss believe that, moving forward, there must be a consistent approach to guidance development and application, with far quicker development of national guidance and greater

levels of assurance and accountability for Trusts and Health Boards which do not adhere to national guidance. There is also a need to address challenges with collecting data on these practices and sharing this transparently. The absence of this data makes it harder for a Trust or Health Board to see how they compare to the wider context, and how out of step they may be.

231. Bliss also believe there should be formal policies around reviewing guidance to ensure it is up to date and reflects wider societal changes to the pandemic. For example, as the pandemic moved past the initial couple of months, and more was beginning to be understood about the virus and its impact, there was no review of how parental access to neonatal wards was being managed. That was despite policies like 'Eat Out to Help Out', the reduction of wider lockdown measures and some evidence that babies in neonatal care were not particularly vulnerable to transmission, nor likely to experience serious ill-health from Covid-19. In future, a more logical review and critical approach to examining why particular policies were in place is needed, particularly given their significant impact on neonatal babies/staff/parents. As set out above, one of the most enduring policies was that only one parent was able to be with their baby at a time, despite those parents living together and often travelling to the hospital together. This created frustration and a lack of "buy in" to the rules.

232. The EPT consider there must be messaging to ensure women and pregnant people with ectopic pregnancy symptoms do not delay seeking medical attention. Similarly, guidance on availability of treatments should be provided as quickly as possible to avoid confusion and people not seeking treatment. These concerns were also shared by the Miscarriage Association.

233. Pregnancy Sickness Support likewise consider that guidance and clear direction from the Government, Public Health England (pre-2021), the Chief Midwifery Officer and other Royal Colleges involved with maternity services in the UK on how the COVID-19 pandemic would affect access to maternity services should have been a top priority. Key stakeholders should have been given a seat at the table to advise Government on how services would need to pivot towards prioritising high risk pregnancy conditions (such as Hyperemesis Gravidarum) and ensuring that communications were clear (once the science became clear) that the benefits of attending units, hospitals and maternity services outweighed any risks of contracting COVID-19.

Healthcare staff

234. Baby Lifeline emphasise further the imperative need to ensure that clinicians **in all areas of the hospital** are made aware that evidence-based guidance does exist for the care of pregnant women and birthing people with COVID-19. The evidence is clear that the majority of pregnant and breastfeeding women and birthing people who died during the Covid-19 pandemic could

have had a different outcome had there been improvements to their care. At all points, there was therefore a need to ensure this demographic received the same level of evidence-based care as non-pregnant women and birthing people. This meant, from an early stage, ensuring pregnant and breastfeeding women and people were not excluded from research and then ensuring that healthcare staff were sufficiently made aware of the research so they could recommend and implement appropriate treatment plans for pregnant women and birthing people. Where the system is put under pressure, Baby Lifeline want to ensure that pregnant women and birthing people are not the ones who slip through the cracks and bear the brunt of system failures in future.

235. Further, the redeployment of health staff should be carefully considered for its wider implications before being implemented. The Lullaby Trust in particular has expressed its firm view that health professionals working in maternity care should be prioritised and not redeployed to other areas of the NHS to ensure that families are adequately supported. Many professionals were redeployed to support Covid-19 wards. Baby Lifeline's "Mind the Gap 2021 report found that over one-third of service providers did not provide tailored training to staff who were redeployed to an area within maternity that differed to their usual role due to the pandemic and staffing pressures. **[Exhibit JW/5, p39 - INQ000399402]** Fewer than nine out of ten providers included 'Covid-19 positive emergency' in their Emergency skills and drills training (87%). Similarly, around three out of four providers included 'assessment and management of a Covid-19 positive woman' in their Maternal critical care training (75%). Seven out of ten organisations offered both subtopics. **[Exhibit JW/5, p38 - INQ000399402].**

236. Many organisations were also particularly concerned about the ongoing impact of pandemic-related shortages amongst maternity care professionals. The Lullaby Trust consider that families may still not be receiving the necessary and lifesaving safer sleep guidance that they would have been given previously in this context. The Miscarriage Association have concerns about the need to ensure adequate staffing levels and care for staff member's needs, such as breaks and support, so that they can avoid burnout for themselves and remain able to provide high quality care for patients.

Greater recognition for charities and the voluntary sector

237. NCT specifically highlight the need for greater recognition of the responsiveness and support provided by charities and the voluntary sector.

238. For NCT, it was critical that the Government recognised support groups and acknowledged the important role that the charity and voluntary sector were playing and could play in the response to the pandemic. It allowed NCT to step in and make a huge difference to new families through Walk & Talk. This learning needs to be included in future planning to ensure greater investment is put in to communicating and engaging with the sector and ensuring that guidance (on what charities can do) is accessible to all.

Telephone triage

239. As set out above at [104] and [202], The EPT's view is that current limited evidence suggests that telephone triage appears to be a safe approach and requires further evaluation.

Support and treatment for pregnancy loss

240. The Miscarriage Association notes that pregnancy loss at any time can be a deeply distressing experience but to go through this alone, without support or treatment options, had a devastating and lasting impact on many people. It specifically recommends:

    a. Access to care:
        i. Better PPE availability and infection-control measures to allow face-to-face appointments wherever possible.
        ii. Where face-to-face appointments are not possible, the use of high-quality telephone consultation and triage, piloted with patients and staff and applied consistently across the UK.
        iii. This care should be provided always by experienced clinicians (nurses, midwives, doctors).
        iv. The provision of clear, honest, understandable and practical advice and information.
    b. Options for management of miscarriage or ectopic pregnancy:
        i. Recognising and empathising with the acute distress caused by not being able to choose between what are already difficult and unpleasant options.
        ii. Providing clear, honest and understandable information and advice about the level of pain and bleeding to be expected, what they might see and what to do with the remains of their pregnancy, and when to seek emergency care.
    c. Investigations and treatment:
        i. Clear consistent guidelines to minimise confusion and variations in provision of treatment.
        ii. Clear roadmaps for the reopening of services as soon as possible and for managing additional demand.
        iii. Clear explanations, empathy and understanding of the impact of recurrent loss or fertility issues and the distress that may be caused by delaying investigations or treatment.

d. Information, empathy and follow-up care:

    i. Ensure that these are standard at all times, but especially so at a time of crisis.

    ii. Communication and interpersonal skills training for all health professionals.

Support for pregnancy sickness

241. Pregnancy Sickness Support considers that the Covid-19 pandemic highlights the need for digitalisation to enable access to support during a pandemic where infection control and lockdowns are necessary for containment of the disease. The NHS' digital infrastructure is lacking tremendously and efforts to move things to online were most successful in trusts that already had provisions for patients to access care digitally. Trusts who were successful in moving online have continued this provision, however others are winding back on these services. COVID-19 accelerated other industries' digital adoption of customer journeys, but the healthcare service is trailing behind.

242. Pregnancy Sickness Support considers women and birthing people with hyperemesis could have been diagnosed by a digital consultation. If urine samples had been requested, they could have been done at home and deposited safely at the GP surgery.[81] However, a diagnosis can be achieved by simply asking the right questions and believing the patient and/or using the PUQE score assessment. All can be done over the phone, prescription issued and crisis for the patient avoided. If another pandemic were to occur, PSS emphasise that in fact diagnosis for this condition is not dependent on urine samples. Ketones measured in the urine are not an indicator of dehydration and therefore in future any barrier to care due to urine samples would be mitigated. PSS reflect that during the COVID-19 pandemic the situation was the same but HG pathways at the time frustratingly still included ketones in urine samples as a pathway to care.

243. Medication could have been prescribed online and access to an online repeat prescription service is entirely possible with weekly (if necessary) online or telephone appointments to manage progress. A lot of women were being told they could have only 7 days of medication, then they were faced with the challenge of having to start the whole process again, sometimes with a different doctor, with a risk of being met with more dismissive comments, scaremongering about the effects of treatment and in some cases refusal to provide treatment.

244. Upon diagnosis, any referral to hospital could have been managed by the patient, with the emphasis on keeping that patient in hospital for minimum periods of time. Overnight stays should not be necessary and comfortable day patient units can be established to support this. If more funding and resource was invested in creating a day unit admission and space for fluids

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[81] Although a request for a urine sample should not be an indicator of hyperemesis, as the ketones marker is highly inaccurate, and prevents a huge number of women receiving treatment based on this test alone, despite presenting clinically dehydrated.

and antiemetics to be administered, that would have saved a huge amount of time, money, suffering for the patients and importantly during the pandemic, would have kept women and birthing people out of hospital.

VIII. CONCLUSION

245. The PBPOs' expertise in these areas and the level of knowledge about the experiences of women and birthing people, parents and babies during the pandemic is, as set out throughout this statement, significant. I emphasise that each PBPO brings its own expertise and background. If the Inquiry considers it would benefit from hearing more about any of the topics raised, any/all of the individual PBPOs would be willing to provide further written and/or oral evidence.

246. I also wish to re-emphasise that the conclusions on lessons learned, above, are preliminary and the PBPOs intend to expand on these as Module 3 progresses. The pandemic had a hugely significant impact on women and birthing people, parents and babies – we look forward to working with the Inquiry throughout Module 3 to better understand that impact and ensure that all appropriate lessons are learned.

IX. Statement of Truth

I, Jenny Ward, for and on behalf of 13 Pregnancy, Baby and Parent Organisations **('PBPO')** believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed: PD

Jenny Ward for and on behalf of 13 Pregnancy, Baby and Parent Organisations **('PBPO')**

Dated: 11th January 2024