

**IN THE UK COVID-19 INQUIRY**  
**MODULE 3**

---

**SUBMISSIONS ON BEHALF OF THE**  
**PREGNANCY, BABY AND PARENT ORGANISATIONS**  
**FOR THE PRELIMINARY HEARING ON 28<sup>TH</sup> FEBRUARY 2023**

---

**A. INTRODUCTION**

1. These submissions are made on behalf of 13 Pregnancy, Baby and Parent Organisations (**‘the PBPOs’**). On 17<sup>th</sup> January 2023 the Chair designated the group collectively as a Core Participant (**‘CP’**) for Module 3 of the Inquiry.
2. The PBPOs are (1) Aching Arms, (2) Baby Lifeline, (3) Bliss, (4) The Ectopic Pregnancy Trust, (5) Group B Strep Support, (6) ICP Support, (7) The Lullaby Trust, (8) Miscarriage Association, (9) National Childbirth Trust, (10) Pelvic Partnership, (11) Pregnancy Sickness Support, (12) Tommy’s and (13), Twins Trust.
3. Collectively, the PBPOs represent a range of key organisations – all charities – working in the pregnancy, parent support and baby care sector, each of which can assist the Inquiry in understanding the impact on of the pandemic on early pregnancy, intrapartum, postnatal, neonatal, new baby and parent support, baby loss and bereavement and the ongoing legacy upon those services.
4. In the determination of the PBPOs CP status, the Chair stated that *“Module 3 will specifically look at the impact on those requiring care for reasons other than Covid-19 and I am conscious there was a significant impact upon pregnancy related care during the Covid-19 pandemic”*. The PBPOs agree. Indeed, the impact was not just significant, it was devastating. During the pandemic, the PBPOs experienced unprecedented demand for their services and witnessed unimaginable suffering due to the deterioration in person-centred and family-centred care. They noted that people and families coming to them for support faced challenges in accessing adequate early pregnancy, intrapartum, postnatal, neonatal, new baby and parent support, baby loss and bereavement, meaning that pregnant women

and birthing people had to attend clinics, scans and hospital appointments alone, some had to give birth alone or with little support and many received the devastating news that their pregnancy had ended whilst alone without their partner or another for support. For those with multiple or other high-risk pregnancies, who therefore attended more appointments and longer hospital stays, the impact was compounded.

5. We are grateful to the Chair for granting Core Participant Status to the PBPOs and we look forward to assisting the Inquiry with its important task in Module 3. As well as assisting in their status as a joint CP, the PBPOs also have a huge amount to offer in terms of factual evidence. It is respectfully submitted that each could provide significant assistance should Rule 9 notices be issued to them.
6. The submissions are divided into three parts:
  - (i) Section A: Key themes and concerns that the PBPOs submit should be addressed in Module 3;
  - (ii) Section B: Submissions relating to various aspects of Module 3;
  - (iii) Annex: A brief summary of each of the PBPOs.

## **B. KEY THEMES**

7. Each of the PBPOs has a unique focus, however all of them agree that there are a number of key themes and concerns that the Inquiry should investigate in relation to pregnancy, intrapartum, postnatal, neonatal, new baby and parent support, baby loss and bereavement, in order to ensure that (a) the voices of those impacted by the issues identified in these submissions are listened to, (b) the events of the pandemic arising from the deterioration in person and family-centred care are fully recorded, (c) any failings are clearly identified, and (d) in the event of any future pandemic or similar emergency, better services are provided and mistakes are not repeated.
8. The following is a provisional list of issues which are of deep concern to the PBPOs:
  - (i) Antenatal care (during pregnancy): During pregnancy, women and birthing people have faced challenges in accessing adequate antenatal care including, but not limited to, accessing information and having to attend clinics, scans and hospital appointments alone. For multiple and other high-risk pregnancies, where people attend more appointments and longer stays, the impact was compounded.

- (ii) Intrapartum care (during childbirth): Because of visitor restrictions in healthcare settings, women and birthing people faced giving birth alone or with too little support. This was often traumatic, particularly so in the case of complex and/or multiple births. Many hospital trusts suspended services, such as home births and midwife-led units due to, in particular, staff shortages which resulted in restricted and/or reduced choice for women and birthing people about how and where they were able to give birth.
- (iii) Postnatal care (after childbirth): Families have faced challenges in accessing postnatal medical care and infant feeding support. There was a lack of care in the form of the usual midwifery and health visitor visits, as well as limited provision through support groups for new parents. This negatively impacted both parents, who were unable to obtain adequate support when they were vulnerable, and upon babies who had limited interactions inside and particularly outside the home during lockdowns.
- (iv) Neonatal care (for newborn babies): Most neonatal units heavily restricted parental presence, for example only allowing one parent to attend or banning fathers/non-birthing parents altogether. This negatively impacted the short and long-term health of babies and developmental outcomes, as well as on family attachment and bonding. There were devastating restrictions on parents being able to be with their premature and sick babies in neonatal care units, some of which would have been compounded by multiple births. The absence of this close parental presence and care will have affected the early days and weeks of tens of thousands of babies, had a significant impact on parents' mental health and wellbeing and their ability to be involved in care and their ability to parent together.
- (v) Death and bereavement: Many women and birthing people received the devastating news that their pregnancy has ended, for example by miscarriage, whilst they were alone. They would sometimes have to share this news with their partners in hospital carparks rather than in the presence of medical professionals. Parents were denied compassionate bereavement care and some were even denied the right to be with their baby until their baby's death.

- (vi) Vaccination: Confused and conflicting messaging around vaccination has led to large numbers of pregnant women and birthing people remaining unvaccinated, resulting in unnecessary increased hospitalising and deaths in this clinically vulnerable group that could have been avoided.

## C. SUBMISSIONS

### *(1) The Module 3 Scope should be expanded*

9. The provisional outline of the scope for Module 3 should be expanded to include issues which relate to antenatal and postnatal care. Antenatal and postnatal care is explicitly part of the Terms of Reference ('**ToR**') and should therefore be included – and expanded upon – in the Module 3 scope. The reasons for this submission are as follows.
10. The Inquiry's draft Terms of Reference published on 11<sup>th</sup> March 2022 did not include any reference to maternity services or babies. As part of the ensuing public consultation, the Pregnancy and Baby Charities Network, of which all 13 of the PBPOs are members<sup>1</sup>, wrote to the Chair on 30<sup>th</sup> March 2022 requesting that the impact upon new and expectant parents and their babies during the pandemic was added to the ToR.
11. The Inquiry's Terms of Reference Consultation Summary Report (May 2022) included the following relevant section:

*“Babies and maternity services — the impact of the pandemic on babies was frequently noted, with respondents asking the Inquiry to consider the implications of restrictions on in-person postnatal midwife and health visits, and the impact on social and physical development of babies from limited interaction outside the home during lockdowns. Respondents also raised concerns about the mental health impact on parents from difficult experiences during pregnancy — such as attending scans and giving birth without the support of a partner being present.*

*In light of the overwhelming weight of opinion during the consultation, Baroness Hallett agrees that the draft Terms of Reference should be amended to allow expressly for a*

---

<sup>1</sup> There are other members of the network which are not part of the PBPOs group.

*wider consideration of the impact on children and young people. She therefore recommends the insertion of the following specific areas of consideration within the first aim of the Inquiry, in the Terms of Reference:*

*[...]*

- *antenatal and postnatal care.”*

[emphasis added]

12. The final Terms of Reference (**ToR**) accordingly included “*antenatal and postnatal care*” as one of the 11 issues to be investigated in relation to the “[t]he response of the health and care sector across the UK”. The Inquiry must investigate all of the issues in the ToR in order to fulfil its statutory obligation to fulfil its terms of reference.
13. The PBPOs were therefore extremely concerned to see that the Provisional Scope for Module 3 makes no reference to antenatal and postnatal care. The Provisional Scope should reflect and – where necessary – expand upon the issues identified in the terms of reference. Indeed, the Provisional Scope closely reflects the issues listed at (1)(b) of the ToR, and includes direct reference to all of the issues which are not the subject of planned additional modules, namely:
- (i) “*preparedness, initial capacity and the ability to increase capacity, and resilience*” (ToR (1)(b)(i)) is covered by Provisional Scope §3;
  - (ii) “*initial contact with official healthcare advice services such as 111 and 999*” (ToR (1)(b)(ii)) is covered by Provisional Scope §4;
  - (iii) “*the role of primary care settings such as General Practice*” (ToR (1)(b)(iii)) is reflected in Provisional Scope §4;
  - (iv) “*the management of the pandemic in hospitals, including infection prevention and control, triage, critical care capacity, the discharge of patients, the use of ‘Do not attempt cardiopulmonary resuscitation’ (DNACPR) decisions, the approach to palliative care, workforce testing, changes to inspections, and the impact on staff and staffing levels*” (ToR (1)(b)(iv)) is covered by Provisional Scope §§5-6
  - (v) “*the consequences of the pandemic on provision for non-COVID related conditions and needs*” (ToR (1)(b)(x)) is covered by Provisional Scope §5

- (vi) “*provision for those experiencing long-COVID*” is covered by Provisional Scope §12.

14. Therefore, the only issue which appears under (1)(b) in the ToR but is not covered in the Provisional Scope, and which is not subject to a separate module, is “*antenatal and postnatal care*”. This must be rectified so that:

- (i) the Inquiry fulfils its ToR – there is currently no planned separate module for antenatal and postnatal care so Module 3 is the only module which will examine the issue;
- (ii) it is clear to persons and organisations who have relevant information and evidence to be able to commence their preparations (as Counsel to the Inquiry at §31 their note of 14<sup>th</sup> February 2023 identify as an important aim of the Provisional Scope), and where appropriate such persons and organisations can offer assistance to the Inquiry. At present, those reading the Provisional Scope will not realise that antenatal and postnatal care will be covered in Module 3;
- (iii) the “*overwhelming weight of opinion*” which led to the Chair proposing to amend the ToR and add reference to antenatal and postnatal care following the Spring 2022 consultation is properly reflected even at this early stage of planning for Module 3. At present, and inexplicably, there is no obvious plan for the voices of those who experienced trauma and loss as identified above to be heard during Module 3.

15. For the above reasons, the PBPOs propose that the following text is added to the numbered list in the Provisional Scope under the words “*In particular, this module will examine*”:

*“Pregnancy, antenatal (before childbirth), intrapartum (during childbirth), postnatal (after childbirth)<sup>2</sup>, and neonatal (newborn baby) care, parent support, baby loss and bereavement, in particular, the impact of that care on babies and parents caused by, for example, the limits on visiting those in hospital such as parents and premature and sick babies, the reduction of in-person care and the information given in relation to vaccination during pregnancy.”*

---

<sup>2</sup> The “plain English” translations of antenatal, intrapartum and postnatal are important as this is a public-facing document and should not include medical terms without them being explained.

## ***(2) Considering the entirety of the United Kingdom in Module 3***

16. The CTI Note states at §19:

*"This Inquiry is obliged under section 27 of the Inquiries Act 2005 and its Terms of Reference to consider both reserved and devolved matters in respect of Scotland, Wales and Northern Ireland. Module 3 will consider the entirety of the United Kingdom so that there is a wider understanding of the impact of the pandemic across the United Kingdom, with differing healthcare structures across the four nations. This will help the Inquiry make meaningful and practical recommendations. This Inquiry's intention, in relation to Scottish matters, is to seek to minimise duplication of investigation, evidence gathering, and reporting with the Scottish Inquiry which has been established to look at matters devolved to the Scottish government".*

17. It is not clear from CTI's Note whether there will be separate parts of Module 3 relating to the devolved nations, as there are in relation to Module 2 (through Modules 2A, 2B and 2C). The PBPOs collectively have significant reach across the four nations and are keen for the Inquiry to set out more detail on how Module 3 will address the differences across the four nations, particularly given that healthcare is a devolved matter. It may be that it is not necessary to divide Module 3 in the same way as Module 2, however it is the PBPOs submission that some separate consideration and evidence gathering (including hearings) in the devolved nations will be necessary in order to fulfil the intention to "*consider the entirety of the United Kingdom*" and would appreciate clarification of how the Inquiry intends to achieve this.

## ***(3) Expert material and the instruction of expert witnesses***

18. In relation to §§53-58 of CTI's note, the PBPOs appreciate the indication that experts will be appointed by the Inquiry in Module 3 and that CPs will be given an opportunity to provide observations on which specialist areas in relation to which lay and expert witnesses are likely to be giving evidence (§58) on the identities of experts (§56) and the questions and issues that they will be asked to address (§56). However, for this consultation to be meaningful, the PBPOs make the following requests:

- (i) That the “*specialist areas*” which have been provisionally identified by the Inquiry are disclosed as soon as possible so that the PBPOs can comment upon them;
- (ii) That the identities of experts who the Inquiry is minded to instruct, and which are relevant to the issues of interest to the PBPOs, are disclosed to the PBPOs in advance of those experts being instructed (§56 of the CTI note is vague as to when this will happen (“*before the expert reports are finalised*”). A consultation on the identity of an expert would be of no or very little use if that expert has already been instructed by the time the consultation takes place. A late consultation with CPs may also lead to problems being identified which lead to an expert being de-instructed, causing unnecessary cost to the Inquiry;
- (iii) The questions and issues experts are asked to address are disclosed to the CPs before they are finalised, not before the report itself is finalised. This will allow the CPs to meaningfully input into the questions. Where CPs are subject matter experts – as the PBPOs are – they are in a position to make constructive suggestions, but the earlier this can take place in the process, the better.

19. In any event, the PBPOs submit that the Inquiry should include antenatal, intrapartum and postnatal care in its list of specialist areas in relation to which lay and expert witnesses should give evidence in Module 3, and would be happy to work with the Inquiry in identifying appropriate experts including assisting on the issues and questions which they are asked to address.

***(4) The process for applying for public funding***

20. In the Chair’s decision of 17<sup>th</sup> January 2023 to designate the PBPOs as a Core Participant, she stated that directions would be given in relation to applications for an award under s.40(1)(b) of the Inquiries Act 2005 of expenses to be incurred in respect of legal representation at the preliminary hearing.

21. Preliminary hearings involve a significant amount of preparation including conference/s with lay clients, drafting submissions, considering the submissions of CTI and other CPs, and attendance at the hearing. The practical effect of not making directions before the preliminary hearing is that where a newly designated CP cannot afford legal representation, a significant obstacle is put in the way of their effective participation. If they cannot afford



lawyers, then they will by definition find it difficult or impossible to secure representation for the hearing. This could prevent their effective participation and also lead to inequality of arms as compared to other CPs such as public authorities which will not require any award under s.40 of the 2005 Act.

22. Although this will make no practical difference in relation to Module 3, the PBPOs propose that going forward, the Inquiry consider making directions for s.40 applications at the point when CP status is granted rather than at the preliminary hearing itself.

#### **D. CONCLUSION**

23. The PBPOs hope that these submissions are of assistance.

**ADAM WAGNER**

Counsel for the PBPOs

Doughty Street Chambers

21<sup>st</sup> February 2023

## ANNEX

### BRIEF INTRODUCTION TO THE 13 PREGNANCY, PARENTING AND BABY ORGANISATIONS

24. The following summaries are intended briefly to introduce the 13 PBPOs. More information on their valuable work can be found on the organisation's websites which we encourage the Inquiry team and members of the public to visit.

#### *(1) Aching Arms<sup>3</sup>*

25. Aching Arms is a charity that gives comfort bears to hospitals and hospices, for midwives and nurses to offer to bereaved parents in their care. Along with the bears, they also offer a support service to parents after their loss, whether it was during pregnancy, at birth or soon after. The charity currently works with over 170 hospitals in the UK, as well as an increasing number of hospices, support groups and funeral directors. Aching Arms is also raising awareness of the impact of pregnancy and baby loss. They are active in advocating improvement in bereavement care in both health settings and the workplace. To this end, the charity has developed and runs training for health professionals, employers and people managers.

26. During the pandemic, Aching Arms noted that the normal level of care from midwives and specialist bereavement teams were severely curtailed. The charity obtained funding for Supporting Arms, a parents bereavement support service, to fill the gap in support, also supported the Royal College of Nursing and Royal College of Obstetricians and Gynaecologists.

#### *(2) Baby Lifeline<sup>4</sup>*

27. Baby Lifeline is a national charity that supports frontline NHS staff to prevent injuries and deaths in and around childbirth. The charity's aim is to improve safety in maternity for mothers, birthing people, babies, and frontline maternity professionals. They do this by

---

<sup>3</sup> [Aching Arms – the charity bringing comfort after baby loss](#)

<sup>4</sup> [Baby Lifeline](#)

providing training related to avoidable harm, by purchasing and developing much-needed equipment, and by conducting relevant research. The charity is a conduit between frontline professionals, representatives from healthcare, patient safety, and law (through its Multi-Professional Advisory Panel); and families (through its Family Voices Group). It also lobbies for change at parliamentary level and is a valued member of national advisory panels for NHS Resolution, the Maternity Transformation Programme (NHS England), the National Perinatal Epidemiology Unit (University of Oxford), and the Pregnancy and Baby Charities Network.

28. During the pandemic, Baby Lifeline set up a Covid-19 Advice Hub, which took the evidence-based guidance from the Royal College of Midwives and the Royal College of Obstetricians and Gynaecologists, and put it into easy-to-understand, positive messaging for women, birthing people, and their partners. The charity also carried out research into the ongoing continuing professional development for maternity professionals during the pandemic.

### **(3) Bliss<sup>5</sup>**

29. Bliss exists to give every baby born premature or sick in the UK the best chance of survival and quality of life. The charity champions babies' right to receive the best care by supporting families, campaigning for change, supporting professionals, and enabling life-changing research. Bliss was founded in 1979 by a group of concerned parents. Over 40 years later Bliss has grown into the leading UK charity for the 90,000 babies born needing neonatal care every year.
30. During the pandemic, Bliss quickly pulled together a position statement to push for Trusts and Health Boards to relax parent access restrictions and to call for national guidance and a consistent approach. These restrictions treated parents as visitors and led to the prolonged separation of parents from their sick babies. The charity updated these statements throughout the pandemic, and they were frequently endorsed and referenced in guidance from the British Association of Perinatal Medicine, the professional body for those working in neonatal care. Bliss developed a remote video-call emotional support service for families.

---

<sup>5</sup> [For babies born premature or sick | Bliss](#)

The charity provided a comprehensive suite of regularly updated parent information about Covid-19 and updates about national policy change and changes to neonatal services. The charity changed its approach to working with neonatal units to secure Baby Charter accreditation to ensure only those units with unrestricted access could progress and supported research applications and provided support to projects which were looking to understand the impact of Covid-19, including the BPSU Neonatal Complications of Covid-19 study.

#### ***(4) The Ectopic Pregnancy Trust<sup>6</sup>***

31. The Ectopic Pregnancy Trust is a charity specialising in ectopic pregnancy, a condition where a fertilised egg implants outside the cavity of a woman's uterus. The condition is common and affects around 1 in 80 pregnancies. The charity supports women and pregnant people and their families through this traumatic experience and strives to raise awareness of the condition. It works to improve diagnosis and treatment by representing lived-experiences to the medical profession, researchers, and influential groups like journalists and the Government. The charity supports research including working with King's College London on a study on early pregnancy loss during the Covid-19 pandemic.

32. During the pandemic, the charity responded to queries from symptomatic women on seeking medical assistance during the pandemic and specifically in lockdown; supported women and partners going through diagnostic tests, particularly as women were undergoing scans and blood tests and receiving bad news alone with partners excluded from hospital settings and interactions; provided general information on treatment availability and options in light of rationalisation of early pregnancy services and making decisions/attending appointments and having treatment (often emergency surgery) alone; and continued support services through increased levels of demand.

#### ***(5) Group B Strep Support<sup>7</sup>***

33. Group B Strep Support is a charity and the UK's leading source of support for families and health professionals affected by group B Strep ('GBS'). The charity uses evidence-led

---

<sup>6</sup> [The Ectopic Pregnancy Trust - Support For You And Your Loved Ones](#)

<sup>7</sup> [Group B Strep Support – Working to stop group B Strep infection in babies \(gbss.org.uk\)](#)

information to educate the public, doctors and midwives about GBS and provide information to affected families. GBS is a bacterium carried by up to 40% of adults with no symptoms. It can, however, cause serious health problems and, tragically, deaths. Babies are particularly vulnerable; it is the most common cause of serious infection in newborns, causing sepsis, pneumonia and meningitis. On average, four babies die and six are left with long-term disabilities every month in the UK. These infections are usually preventable with the right support.

34. The charity's vision is to eliminate GBS infection in babies in the UK by (1) making help, support and information available to new and expectant parents, and others affected by GBS in the UK, (2) to raise awareness of GBS amongst health professionals, especially midwives, through educational initiatives, (3) to improve GBS identification, prevention and treatment, and (4) to support organisations promoting research into GBS and to publish the useful results of such research. The charity provides support through its national Helpline.

#### ***(6) ICP Support<sup>8</sup>***

35. Established in 1991, ICP Support is the only UK-based charity that specifically supports women suffering with intrahepatic cholestasis of pregnancy ('ICP'), a condition that can cause stillbirth. The charity provides the most up to date and specialised information on ICP in the world, which significantly improves the quality of life for people affected by ICP each year. It provides support through social media support platforms as well as by email and telephone. The charity's vision is that every ICP baby is born safely, and this is achieved through (1) providing information and support to people affected by ICP, (2) raising awareness of ICP, and (3) promoting and funding research into ICP.

36. During the pandemic, the charity provided one-to-one Zoom calls for anyone affected by Covid-19. Calls to the charity's support line during 2020 rose by 42%. During this time some women were being denied the specific blood tests that they needed to either diagnose ICP or to assess fetal risk for the baby from the condition. This resulted in increased anxiety

---

<sup>8</sup> [ICP Support](#)

for them in addition to the worry about Covid-19 itself. The charity's role was to support them so that they could ensure that these tests did happen.

### *(7) The Lullaby Trust<sup>9</sup>*

37. The Lullaby Trust is a charity that saves babies' lives and supports bereaved families. Around four babies per week still die from sudden infant death syndrome ('SIDS') and the Lullaby Trust is committed to bringing that number down to zero. Through educating parents on how they can reduce the risk of SIDS and investing over £12million in research, the charity has played a key role in reducing the number of babies who die from SIDS by 83%, saving the lives of more than 29,000 babies. Each year the charity trains thousands of health professionals to support parents in sleeping their baby safely, work directly with parents, giving safer sleep advice through our helplines and social media, which was particularly vital throughout the pandemic. They work with young parents through our Little Lullaby project and produce resources for specific audiences, including but not limited to, those in emergency accommodation and, with the charity's recently published winter resource, guidance to help families follow safer sleep advice when they may not be able to heat their homes. The Lullaby Trust also supports bereaved families, through their helpline, family days and befriending scheme. In addition to this, they work with the NHS to provide a Care of Next Infant Programme which offers a lifeline to bereaved families expecting a new baby.
38. During the pandemic, the charity's services and the families who contacted the charity were impacted by the lack of access to health professionals who were deployed to other areas of the health service. The charity's Bereavement contacts, as well as their Information and Advice contacts, grew by between 51% and 132%. The charity saw a large increase in demand in enquiries from new and expectant parents. New parents were not accessing the same support groups, both antenatally and postnatally; places where they would usually receive safer sleep messaging, advice and support. They noticed that the calls to the helpline for safer sleep information were longer and parents asked many questions about safer sleep, rather than calling for a one topic enquiry. They also saw an increase in the number of mothers contacting them for support who were reporting high levels of anxiety. They

---

<sup>9</sup> [The Lullaby Trust - Safer sleep for babies, Support for families](#)

created a web page they created about bereavement in the pandemic which shared information and concerns reported by parents.<sup>10</sup> The charity also introduced a Webchat service in September 2020, which allowed bereaved families to access one-to-one support without having to schedule a phone call. The charity's Care of Next Infant Programme was also affected, as healthcare professionals who usually deliver this vital service were deployed elsewhere. This was devastating for families that needed extra support, having already experienced the death of a baby within their family.

#### ***(8) The Miscarriage Association<sup>11</sup>***

39. The Miscarriage Association is a charity that offers support and information to anyone affected by miscarriage, ectopic pregnancy<sup>12</sup> or molar pregnancy<sup>13</sup>. The experience of any of these losses can be shocking, frightening, physically painful and deeply distressing. The Miscarriage Association helps people through by offering (1) a staffed helpline (phone, email, live chat, direct messaging), (2) a range of leaflets on pregnancy loss facts and feelings, (3) a peer support network, including face to face and online support groups, (4) a well-regarded website filled with information, support and places for remembrance, (5) campaigns to raise public awareness of pregnancy loss, and (6) support for clinical and qualitative research.

40. In relation to the Covid-19 pandemic, the charity made immediate changes to its website, creating a Covid-19 information hub with FAQs, links to official guidance and information about how the pandemic was impacting access to care. This was updated frequently as guidance and access changed and in line with questions and concerns. The charity also maintained its staffed helpline throughout, noting a 37% increase in direct contacts, and fed information into the All Party Parliamentary Group on Babyloss and to the Scottish government.

---

<sup>10</sup> <https://www.lullabytrust.org.uk/bereavement-support/bereavement-during-the-coronaviruspandemic/>

<sup>11</sup> [The Miscarriage Association: Pregnancy loss information and support](#)

<sup>12</sup> An ectopic pregnancy is one that develops in the wrong place, usually in one of the fallopian tubes. A tubal pregnancy can be life threatening, causing the tube to tear with subsequent internal bleeding. It can also reduce future fertility as well as increasing the risk of a further ectopic.

<sup>13</sup> A molar pregnancy is an abnormal conception in which the baby does not survive but other cells in the uterus develop very rapidly. These can develop into a form of cancer (choriocarcinoma), so women require specialist follow-up and are told not to conceive until follow-up is complete.

***(9) National Childbirth Trust ('NCT')<sup>14</sup>***

41. NCT's mission is to support parents through the first 1,000 days to have the best possible experience of pregnancy, birth, and early parenthood. NCT progresses this through three interconnected aims: (1) Sharing evidence-based information to support parents to make informed decisions; (2) creating networks of vital support and life-long friendship; and (3) campaigning on the issues that matter most through the early experiences of becoming a parent. NCT supports parents through provision of antenatal and postnatal courses, and thousands of free community-based activities and events, often run by NCT's volunteers. The charity offers unbiased information and support to thousands of parents via our Infant Feeding Line, in homes and in the community. NCT's website provides evidence-based information and resources on the issues that matter to parents. The charity also provides a range of funded peer support programmes for those facing specific challenges, such as social isolation or poor mental health. NCT works with local and national governments, charities, and corporate partners to consider opportunities to drive change at scale in areas of need for new parents.

42. During the Covid-19 pandemic, especially the period of lockdown when most people were prohibited from meeting others outside their household, new parents were severely affected by isolation from family, friends and direct contact with health professionals. NCT was able to offer help through online courses and phone-based support; constantly updated web-based information about Covid-19 healthcare and vaccination during pregnancy and breastfeeding; and the widespread offer of 'Walk and Talk' groups, organised out of doors for parents and babies, having gained exemption from the restrictions as these offered therapeutic support. NCT charted feedback on our services and via a 2021 survey focusing on postnatal care during the previous year.

***(10) Pelvic Partnership<sup>15</sup>***

43. Pelvic Partnership is a charity offering support and information to women and birthing people experiencing pregnancy-related pelvic girdle pain ('PGP'). PGP can be a severe and painful condition occurring during and/or after pregnancy, causing pain in and around the

---

<sup>14</sup> [The UK's leading charity for parents | NCT](#)

<sup>15</sup> [Privacy policy – Pelvic Partnership](#)



hips and pelvis. In short, PGP can affect every aspect of daily life, causing immobility and leading to associated mental health impacts for up to half of all women and birthing people. The charity raise awareness about PGP and how it can be safely and effectively treated with hands-on manual therapy, such as physiotherapy, osteopathy and chiropractic care. The charity gives women and birthing people the tools and confidence to access treatment for their PGP on our website, free ebook and other downloadable resources and our social media channels. It supports women and birthing people on the path to recovery through its volunteer helpline, Facebook support group and one-to-one support over email, private message on social media and monthly Q&As on our Instagram stories.

44. At the start of the pandemic, the charity noticed a massive influx in the number of women and birthing people reaching out on their helpline and on social media, amounting to a 150% increase in demand for support services year-on-year. As in-person services shut down, women and birthing people with PGP were forced online to access support, information and treatment for their condition. The charity developed and regularly updated Covid-19 guidance in plain English for service users, and a free ebook: "PGP is treatable!", to give women and birthing people to manage their pain as much as possible without access to hands-on treatment.

**(11) *Pregnancy Sickness Support*<sup>16</sup>**

45. Pregnancy Sickness Support is the only UK charity working to improve care, treatment and support for women and pregnant people suffering from nausea and vomiting in pregnancy and the severe form of the condition hyperemesis gravidarum. The charity provides a telephone helpline and digital helplines nationally for information, resources and support for anyone affected by the condition, and offer ongoing one-to-one or group support to sufferers via our volunteer network, often for the duration of our service users pregnancies. The physical and mental impact of the condition can lead to depression, suicidal idealisation or attempts, and even PTSD continuing long after their pregnancy experience. Around 10% of much wanted pregnancies are terminated because of the condition, around 2,000 each year, and we are working hard to reduce this number by providing understanding, compassionate, informative support.

---

<sup>16</sup> [Pregnancy Sickness Support home page - UK Charity](#)

46. During the pandemic, the charity received triple the number of contacts compared to two years previously, with a large quantity of these Covid-19 related. Service users shared issues such as GP surgery closures, refusal of treatment, poor care leading to a notable impact on our service users mental health, with fear of accessing healthcare as they had been dismissed by their healthcare teams due to the pandemic. The charity responded by extending its charities opening hours, employing additional staff, updated safeguarding policies and procedures and working to form links within healthcare environments to signpost to healthcare professionals known to the charity for giving good care. The charity now has a specialist support team within the charity and is about to launch an accessible specialist telephone counselling service to continue to provide support to those who were negatively affected due to the pandemic.

*(12) Tommy's<sup>17</sup>*

47. Tommy's is a charitable organisation committed to saving babies' lives and supporting families through every part of the pregnancy journey. 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 their clinics, currently funding three specialist research centres across the country.

48. During the pandemic, Tommy's (1) carried out research into whether women infected with Covid-19 in later pregnancy were more likely to have birth-related complications, (2) stored and studied samples from women with either suspected or confirmed Covid-19 at Tommy's National Reproductive Health Biobank, (3) through Tommy's Pregnancy Hub undertook specific work to address vaccine hesitancy among pregnant women, and (4) through its midwife helpline provided support to anxious parents and heard about their concerns.

---

<sup>17</sup> [Together, for every baby - Charity for Babies | Tommy's \(tommys.org\)](https://www.tommys.org)

(13) *Twins Trust*<sup>18</sup>

49. Twins Trust (formerly TAMBA) is the only UK-wide charity dedicated to improving the lives of families with twins, triplets or more. The charity's vision is a world where all twins, triplets or more - and their families – feel supported and empowered, whatever they may face. The charity (1) runs courses, clubs and online community groups which bring people together, (2) offers a peer-led helpline and family crisis support for people needing tailored support, (3) provides a specialist bereavement service to support people who have suffered a loss of twins, triplets or more, during or after pregnancy, (4) partners with clinicians, hospitals and maternity units to ensure that everyone expecting multiples has access to the best care, (5) pushes the government to make sure that what they're doing reflects the unique needs of our community, (6) educates healthcare professionals to deliver this care, (7) ensures that families' voices are reflected in national and international research initiatives – and that this translates into real world change.

50. During the pandemic, Twins Trust made sure that people had enough community and support around them throughout this difficult time, for example by extending their crisis service to support new mums in hospital, just home from hospital and anyone else who had lost their support network. Additionally, they ensured that volunteers were matched with parents going through the same experience ie volunteers with NICU experience supported parents with babies in NICU. The charity's provision of information and resources was made much more digitally available. For example, they moved all antenatal sessions online so parents of multiples were still accessing the vital information they needed, ensured that their website had the latest Covid and RCOG information, set up a text information service, introduced virtual clubs and provided webinars on home schooling/behaviour; linked to having kids at home all the time (particularly challenging for parents of multiples).

---

<sup>18</sup> [Twins Trust | Twins Trust - We support twins, triplets and more...](#)