

July 2023

**Zoe Clark-Coates MBE BCAh and Samantha Collinge RM** 

**CP 805** 



## The Independent Pregnancy Loss Review

Care and support when baby loss occurs before 24 weeks gestation

Presented to Parliament

by the Secretary of State for Health and Social Care

by Command of His Majesty

July 2023

CP 805



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The Independent Pregnancy Loss Review (the Review) was commissioned by and reports to the Department of Health and Social Care in England (DHSC). This report fulfils the requirement set out in the Civil Partnerships, Marriages and Deaths (Registration etc) Act 2019 which requires The Secretary of State to make arrangements for the preparation and publication of a report on whether, and if so how, the law ought to be changed to require or permit the registration of pregnancy losses which cannot be registered as still-births under the Births and Deaths Registration Act 1953.

Our Terms of Reference also included looking at options to improve NHS gynaecology and maternity care practice for parents who experience a miscarriage and other causes of baby loss. Our recommendations extend to England in relation to matters that are devolved in Wales (including health), and England and Wales in relation to non-devolved matters (including registration).

### **Acknowledgements**

This Review exists due to the Chancellor of the Exchequer, the Right Honourable Jeremy Hunt MP; his belief that bereaved families deserve better led him to launch this independent review, when he was in the role of Secretary of State for Health and Social Care. We thank Number 10 for supporting us, our work, and this Review. We would also like to acknowledge Tim Loughton MP, whose passion for driving change led him to launch the Civil Partnerships, Marriages and Deaths (Registration etc) Bill (now Act 2019)<sup>1</sup> that led to this Review.

We thank Professor Jacqueline Dunkley-Bent OBE for her support and Baroness Floella Benjamin DBE for her constant belief in us and our work. Thank you to Parliamentary Under-Secretary of State Maria Caulfield MP and the Secretary of State for Health and Social Care, the Right Honourable Stephen Barclay MP, for supporting this Review and being committed to its implementation and change. We can do better as a country in supporting anyone affected by baby loss, and those in leadership are responsible for changing the system so that it is better for this generation and future generations.

Finally, and just as importantly, we want to acknowledge the families who shared their personal stories with us. You have bravely shared intimate details of your experiences and told us about the care that you received, both good and bad. In your desire to ensure that others experiencing baby loss do not have to suffer the same pain and heartbreak that you have endured, you have been willing to reopen traumatic wounds and expose areas of care that need radical change. Each of you was determined that your journey and your baby's life would be recognised and honoured; for that we are extremely grateful. Thank you from us and thank you from every other bereaved family.

#### **Advisory Panel**

We would like to thank all members of the Advisory Panel, who gathered at the commencement of this Review. Thank you for sharing your thoughts and discussing the scope of the review with us.

The Advisory Panel met four times at the start of the review process, were shown a draft version of the recommendations, a near final draft of the complete review, and were then invited to feedback prior to its publication.

#### A personal message from Zoe Clark-Coates MBE BCAh

When I first trained as a counsellor and grief specialist nearly thirty years ago, I had no idea that this would form the backbone of my work. Today, as a leading expert on trauma and grief, a best-selling author on loss, a campaigner, the CEO of The Mariposa Trust (known by the name of our primary support division sayinggoodbye.org) and just as importantly as a woman with lived experience of baby loss, I took on this role determined to action lasting change.

The Mariposa Trust (Saying Goodbye) has for the past ten years been at the forefront of offering bereavement care and support to anyone affected by baby loss, at any stage of pregnancy, at birth or in infancy, whether the loss is recent or historic, and those journeying subsequent pregnancies. Through this work, we have been privileged to walk with tens of thousands of families and support them as they grieve. Weekly, I hear hundreds of stories from people, stories of heart-warming compassionate care, and sadly stories of horrendous treatment. I have seen first-hand the difference good support can make, but I have also witnessed the scars of many families tragically let down by the system; because of this, I have committed my life to eradicating this 'roulette wheel' of quality, and the mission of the Mariposa Trust (Saying Goodbye) is to make this happen. Every person deserves the best medical care, coupled with first-class emotional support. Once the recommendations in this review are implemented, I hope we will finally see that come to pass.

Since its inception, The Mariposa Trust (Saying Goodbye) and I have campaigned for excellent bereavement care and the introduction of a certificate of life to be given to the parents of all babies who die before 24 weeks. Following years of hard work, on the 6<sup>th</sup> of July 2017, the charity saw its Bill for a certificate of life be introduced to The House of Lords by Baroness Floella Benjamin DBE. The five babies my husband and I lost in pregnancy have never had official recognition, they don't appear on our family tree, and we feel this is wrong. I passionately believe that if we honour and acknowledge babies that have died, we can achieve two things. Firstly, we give parents the acknowledgement they often need that their baby did exist and does matter. Secondly, we change the misconception that baby loss is simply a medical issue when it is the loss of a life and often a traumatic and heart-breaking medical incident. Love starts when a person sees the two lines on a pregnancy test, and when their baby doesn't get to stay, it can change people forever; it's time that the government and society formally recognise this.

Over the past five years, Sam and I have met with hundreds of medical personnel, countless experts, professionals, charities, community workers and, importantly, bereaved families. We have visited hospitals across England and sat in clinics, appointments, wards, operating theatres, and staff rooms. We have attempted to leave no stone unturned in our search to reveal the care currently offered to bereaved families in and outside hospitals. We have extensively explored the type of care we should be trying to achieve as a country. We have looked at 999, 111, GP care, education, workplace support, and so much more.

Due to the impact of Brexit and the pandemic, this review was sadly paused and delayed due to other pressures at the DHSC, but this additional time has allowed us to adapt recommendations to this new climate. It has also allowed us time to review

the care of the bereaved through the Covid-19 pandemic in the hope that mistakes made will not be repeated in the future.

Often the loss of a baby tragically can't be stopped, but the experience of loss can be made more manageable, and we must ensure this is delivered. I hope this review is a catalyst for radical change, and I look forward to assisting in its implementation in England through the outworking of this review and my work for the Mariposa Trust.

#### A personal message from Samantha Collinge RM

Since I was appointed as a bereavement midwife in 1998 I have tirelessly campaigned for a standardised care pathway that ensures that every parent experiencing baby loss (regardless of the gestation or type of loss) receives the physical and emotional care and support they deserve. In recent years, through my involvement with the All-Party Parliamentary Group for Baby Loss and The National Bereavement Care Pathway, I have been heartened to witness many positive advances in care provision for bereaved families. However, these improvements in care tend to be for individuals experiencing later loss i.e. stillbirth and neonatal death and are sadly not shared with those families experiencing miscarriage, ectopic and molar pregnancy.

2023 is a year that will mark several significant milestones in my life:

- It is 40 years this year since I began my career in the NHS as a student nurse.
- It is 25 years since I was appointed as a bereavement midwife, one of the first in the UK.
- 2023 also marks 30 years since I had my first miscarriage.

To this day I still remember in vivid detail how utterly devastated my husband and I were at the loss of our first baby, yet what was more shocking to both of us was the total disregard by staff for the emotional impact that the miscarriage had on us and how our loss was minimised and treated merely as a 'clinical event'.

Apart from being given a photocopied leaflet that focused on post loss physical symptoms, I was offered no information on why the loss might have happened and was simply informed that "it's just one of those things" and encouraged to "try again."

At no point did anyone ask me or my husband how we were feeling.

During my many years working as a nurse and a midwife I have witnessed countless shocking clinical events along the early loss pathway. I have also heard from far too many individuals who have been left traumatised by their poor experience of care.

After five years of conducting this review, I would dearly like to be able to report that things are very different 30 years on from my own personal experience of loss and that there have been massive improvements in both clinical and psychological care and support. Sadly, this is not the case. Even in my role as a bereavement midwife, I was recently accused of being over emotional when I challenged the insensitive processes that still exist in early loss care provision.

The Review offers a real opportunity to change this culture and I feel enormously privileged to have been invited to co-lead this piece of work.

I would like to pay tribute to the courage of the bereaved parents who so freely shared with us their often-harrowing stories of loss through their own desire to see and bring about change.

Similarly, we are indebted to the plethora of passionate and dedicated healthcare professionals, organisations and charities who sacrifice their own psychological wellbeing on a daily basis in working with and striving to improve things for families experiencing baby loss.

To ensure that this vital learning from families and care providers is suitably implemented, Zoe and I would like to lead a Pregnancy Loss Review working group to guide and implement the recommendations contained within this report.

# Executive Summary – Our vision for high-quality baby loss care

Everyone is affected by early baby loss. Those who have not personally experienced it will know of a relative, a friend, a work colleague, or an acquaintance who has experienced baby loss before 24 weeks gestation. These losses may be due to miscarriage, ectopic or molar pregnancy, or because parents have made a heart-breaking decision to terminate a much-wanted pregnancy after receiving a diagnosis that their baby has a serious congenital anomaly.

Many of the people who contributed to this Review have been traumatised by their baby loss experience, and we are grateful that they have chosen to share their stories with us. We heard how early loss is commonly viewed as a 'clinical episode' and how some healthcare professionals do not take individuals' emotional and physical pain seriously. Very few women we spoke to had had any offer of emotional support or mental health screening, and this was even less in the case of their partners.

We learnt how women are constantly being bounced between GPs, 111, Accident and Emergency (A&E), gynaecology and maternity services, and we heard harrowing accounts of women being made to wait in public spaces, often bleeding through their clothing, whilst sitting alongside pregnant individuals and their partners. Disturbingly, we heard from many women who had miscarried at home on how they were advised to retrieve their baby's remains from the toilet and how they had been advised to store their baby's remains in a Tupperware container in their fridge at home until their local early pregnancy loss unit was open, which was often for multiple days.

We are aware that many Trusts have care pathways in place, whether their own or national, and are making substantial advancements in the bereavement and clinical care that they provide. This Review seeks to ensure that all Trusts and organisations can offer a consistent and forward-thinking service, that excellent care is acknowledged and rewarded, and that areas of concern are highlighted so that improvements can be made.

When tasked with writing this independent 'Pregnancy Loss Review' by the Secretary of State for Health and Social Care, it was tempting to only recommend things that could be easily delivered, but this is not what we were asked to do. We were instructed to consider what 'good' compassionate care could look like, and to not only identify gaps in service provision, but also to examine why families have been failed time and time again and the reasons why staff members have not been supported in their high-pressure roles. This has resulted in us producing what could be considered a long list of recommendations, some of which we hope will be implemented immediately, whilst others would need to form part of a long-term strategy. We fully understand and appreciate that many of the recommendations will involve significant investment in infrastructure, workforce and digital transformation, but we have been reassured in the meetings we have conducted that the

Government, DHSC and NHS England (NHSE) are committed to effecting lasting change, and so we trust that the investment will be made.

We have avoided endorsing individual organisations and charities by name within the recommendations as we are acutely aware that there are many national and local organisations doing incredible work, and it was not possible to mention them all. We have however highlighted some national and local organisations within the body of the report to ensure best practice and good work is recognised and acknowledged.

This report sets out our vision for improving the care of people who experience pre-24-week baby loss. It describes a system in which:

- Everyone receives high-quality education about pre-24-week baby loss before they become pregnant through the statutory Relationships, Health and Sex Education curriculum.
- All people groups, regardless of race, colour, age, gender, sexual orientation, or religion have their voices heard, and choices upheld.
- There is clarity about whom to call and where to go when pain and bleeding occur at any stage of pregnancy and what to expect during and after baby loss.
- Access to compassionate clinical care in appropriate healthcare settings is available 24 hours a day, seven days a week, through networked services.
- All parents receive clear, consistent information and support enabling them to make decisions about their physical and mental health care needs during and after baby loss.
- Care is compassionate, individualised, and respectful of personal, cultural, religious and language preferences. Parents and their babies (including baby loss remains at any gestation) are cared for with dignity and respect.
- Regardless of gestation, all bereaved parents are offered choices regarding creating memories of their baby and options regarding marking their loss, such as funerals or memorial ceremonies as appropriate.
- Women and partners experiencing loss are routinely offered mental health support following a loss and should have access to specialist counselling and mental health services where appropriate.
- Bereaved parents can, on request, receive a Baby Loss Certificate from the Government, whether their loss was recent or historic.
- Following a baby loss, individuals and couples are supported to understand
  why the loss occurred and are offered a follow-up appointment to discuss the
  results and implications of any investigations. A robust management plan
  must be in place for subsequent pregnancies; this may include referral to a
  specialist consultant obstetrician/gynaecologist.
- All healthcare professionals working in baby loss services receive multidisciplinary mandatory bereavement care training and information, including education on the importance of psychological well-being and self-care for staff

- to ensure they can provide the highest quality of care. Staff should be allocated time to attend, and their compliance should be monitored.
- Employers recognise the impact of baby loss on employees, and Human Resources (HR) policies are updated to support their staff.
- There are systems in place for employers to manage the potential impacts on the mental health and well-being of all staff employed in workplaces providing baby loss services.

#### Recommendations

The following recommendations are intended to support the Government and the NHS in creating a forward-looking approach to improve the safety and care experience for all those who have a pre-24-week baby loss. Implementing these recommendations is crucial to improving care for people when they are particularly vulnerable. We recommend establishing a 'Pregnancy Loss Review' working party, chaired by us, which will ensure that the recommendations and best practice points within this report are actioned.

The highlighted problems and impacts are based on evidence gained from the broad spectrum of meetings, consultations, and patient/parent feedback, from the work of the review and our professional experience. These problems do not necessarily exist in every primary and secondary healthcare setting, and they are certainly not representative of every healthcare professional. Healthcare professionals working with loss are under huge stress and work under very difficult circumstances, and it is important that we acknowledge this, whilst simultaneously addressing elements of care that need to change.

#### Education, Training, and Information

- 1. The Department of Education must expand the current Relationship, Health, and Sex Education (RHSE) guidance for schools to include education on all types of baby loss, not just miscarriage. The supporting teacher training modules should also include information on symptoms of baby loss, how to access care, and where to access support. Whilst we understand teachers do not want to distress students, it is inappropriate to say that we do not educate people in case we upset them.
- 2. NHS England should commission the development of a poster on 'what to do if you have pain or bleeding during pregnancy' to be made available to GP practices, sexual health clinics, pharmacies, and Women's Health Hubs. The poster should include a QR code to link to more information and should have space for contact details for local services.
- 3. NHS England should work with Trusts and their Maternity Voices Partnerships to review the quality and accessibility of information regarding pre-24-week baby loss, including what information should be given at the first antenatal visit, and what to do and how to access services if there is pain and bleeding in early pregnancy. This information should include a list of local services and

the care they can expect to receive, as well as emergency contact numbers and medical guidance on managing symptoms. People should know what to expect in advance. This information must be available in all languages and in Easy Read and digital formats.

- 4. NHS England Transformation Directorate in partnership with Sam Collinge and Zoe Clark-Coates, should undertake a review of the availability and accessibility of information on 'what to do if you have pain or bleeding in pregnancy' across all NHS digital platforms including <a href="www.nhs.uk">www.nhs.uk</a>, NHS Apps and Maternity Notes Apps (e.g. BadgerNotes) and should take steps to ensure that all information is clear and easily accessible. This should include links to information on how to access baby loss care services 24/7 based on a woman's location and what care they can expect to receive.
- 5. Each Integrated Care System (ICS) should introduce a pre-24-week baby loss support and advice line that is available 24/7. We suggest that regions work together to pool resources, as a network approach may be more cost effective. Where possible, this could be integrated into existing telephone helplines, or maternity helplines. The advice lines will be able to provide crucial advice and support. Patients can then be referred to the most appropriate department for treatment and care at a suitable time. Being given an appointment at an Early Pregnancy Assessment Unit for the following day could save an individual a late-night trip to A&E. The Care Quality Commission (CQC) should monitor that the advice lines have been implemented and are governed and properly maintained.
- 6. Information leaflets, bereavement support books and bereavement resources should be available to bereaved parents to take home, in all primary and secondary healthcare settings, following a pre-24-week baby loss. Leaflets must be available in all languages and in Easy Read and digital format.
- 7. Bereavement care training and education and training in breaking unexpected bad news should be mandatory for all clinical and non-clinical staff working in areas where baby loss occurs. The exception to this should be when an appropriate level of competence can be demonstrated. The training should include experiential personal accounts demonstrating the emotional impact of baby loss, and it should show how compassionate and excellent clinical care can make a substantial difference to patients. Additional training could be delivered via e-learning modules through the Workforce, Training and Education directorate of NHS England, or ideally through face to face training sessions.
- 8. All healthcare professionals who may be in contact with anyone experiencing baby loss should receive mandatory training and education in the importance of sensitive communication to ensure that they are fully equipped to care for patients compassionately. The only exception to this is where staff can demonstrate competency. Staff should also be encouraged to be 'patient-led' in their terminology. This could be delivered via e-learning modules through the Workforce, Training and Education directorate of NHS England. The General Medical Council (GMC) and the Nursing and Midwifery Council

- (NMC) should instruct medical schools, universities and education providers to include this training in their syllabuses.
- 9. Funding must be allocated to allow NHS England to increase the current investment in NHS staff training to ensure that time is protected for all staff to undertake mandatory annual training in bereavement care. This should be for all baby loss, including pre-24-week baby loss. This will ensure staff can access training during work hours.

#### Service Provision

10. Funding must be allocated so that each hospital maternity unit, Early Pregnancy Assessment Unit (EPAU) and A&E department can provide appropriate private spaces for patients experiencing pre-24-week baby loss, that are separate from public waiting areas.

#### Early Pregnancy Assessment Units (EPAUs)

- 11. NHS England should develop guidance for Commissioners of 111 and ambulance services that sets out how to work with Trusts to contract appointments with EPAUs so that patients with pre-24-week complications can be sent directly to an EPAU where appropriate. This practice already happens in some areas but not everywhere.
- 12. All areas with an EPAU should receive clinically stable patients directly from the ambulance service during opening hours.
- 13. People should be able to self-refer to an EPAU with any pain or bleeding during pregnancy, regardless of their gestation, or whether they have a history of previous losses.
- 14. The Royal College of Nursing (RCN) and Royal College of Obstetricians and Gynaecologists (RCOG) should build on the 'Nursing Workforce Standards', and expand the current work being undertaken by the RCOG in relation to safer care in maternity services, to develop a workforce planning tool, similar to the 'Birthrate Plus Acuity Tool' for midwives. This would allow safer and more consistent staffing for EPAUs.
- 15. The National Institute for Health Research (NIHR) should commission additional research into EPAU working practices, accessibility, outcomes for women, and cost-effectiveness (including prospects for new community EPAUs), drawing on the 'Variations in the organisation of and outcomes from Early Pregnancy Assessment Units' (VESPA)<sup>2</sup> study and other studies.
- 16. NHS England should develop guidance for regional teams and Integrated Care Systems on how EPAUs might work in networks so that women can access care 24/7 without needing a referral from another healthcare provider. In any area that is unable to offer 24/7 EPAU services, the Trust or Integrated Care Board (ICB) must ensure that the EPAU should operate a minimum of 9am-5pm opening hours Monday to Friday, and reduced hours on a weekend. The guidance should consider different models, such as establishing central

- hubs and EPAUs in community settings and hospitals. These networks should also support learning and the development of expertise across a geographical area. Where additional funding is needed, this should be allocated.
- 17. NHS England must ensure that a Directory of Services (DoS) is created in each region, that is locally owned and regularly updated, to ensure that any patient calling 111 or using 111 online is correctly directed to appropriate clinical care. The DoS should reflect EPAU availability to ensure that women experiencing baby loss are accurately directed to the most appropriate service. Where services do not currently exist, these should be commissioned and funding allocated.
- 18. A minimum time allocation of 30 minutes per appointment within an EPAU should be implemented.

#### Gynaecology Services

- 19. Gynaecology services must be prioritised by each Trust, including the ringfencing of dedicated gynaecology beds co-located in one area, on female-only wards, and funding must be allocated for this.
- 20. Each ICB must provide a Gynaecology Day Assessment Unit (GDAU) that is accessible all day, 7-days a week. This should ideally be attached to or be near to an EPAU. The GDAUs should be staffed by specialist gynaecology staff with the ability to scan when necessary. Funding must be allocated for this.
- 21. Women experiencing pre-24-week baby loss should never be cared for in mixed-sex wards with shared facilities.
- 22. Women experiencing pre-24-week baby loss should be cared for by specialist healthcare professionals who have received mandatory training in bereavement care and support. Training resources are currently available within the e-learning modules through the Workforce, Training and Education directorate of NHS England, and we would welcome the development of more.

#### Clinical Care Quality

#### Physical Health Care

23. National Institute of Clinical Excellence (NICE) must be urgently commissioned to update their early loss guideline: Ectopic Pregnancy and Miscarriage: Diagnosis and Initial Management (NG126) to allow NHS England, to create a pre-24-week baby loss programme and plan for service development and commissioning, to ensure that all updated guidelines are embedded into clinical care. This will then allow each ICS to create a local pathway based upon local needs. Key objectives would be to ensure consistency around clinical care, mental health support, investigation and standards of care, offered to all women. The guidelines must include the following:

- If a home pregnancy test reveals a positive pregnancy result 3-weeks following a baby loss or pregnancy or loss symptoms persist, further medical management should be offered to the individual. This may include a clinical review, repeat urine tests, blood tests to check for pregnancy hormones and/or an ultrasound scan.
- Clear integrated care pathways must be established across primary and secondary care, which must include the updating of IT systems, to allow communication with GP's IT systems to safeguard that GPs, community midwives, and health visitors are notified of a baby loss as soon as it occurs.
- If individuals experience a pre-24-week baby loss, and requests an appointment with their GP practice, a person-centred consultation should be offered to them. If appropriate or requested by the individual, their emotional health and/or implications for future pregnancies should be discussed. Information about the impact on mental health and trauma that may ensue following a baby loss should be provided, and individuals should be advised that they can self-refer to NHS Talking Therapies. Clinicians should actively encourage this self-referral if they feel it would benefit the individual.
- 24. The provision of primary and secondary baby loss services should be audited and evaluated by the ICS. This should be based on a quality standard created by NICE based on their updated guideline.
- 25. Pregnancy after loss clinics should be established in each hospital offering maternity care. These should be staffed by specialist gynaecology nurses and/or midwives and led by a consultant. When a family is expecting a baby following loss, additional clinical and emotional support is often required, and by offering specialist support, individuals feel heard and understood.
- 26. To assist healthcare professionals in the care that they provide, and to prevent individuals having to continually share their experience of loss, a new standardised 'Baby Loss Lanyard' should be produced and made available to women through the community midwife, A&E or EPAU. We have included a lanyard within the 'CCC Kit' recommendation (rec 38), but this also needs to be separately available for those who are not given a 'CCC Kit'.

#### Mental Health Care

- 27. We recommend that further research, evaluation and piloting is required to develop screening tools and pathways for women and their partners suffering with mental health illness, as a result of baby loss. Studies have demonstrated the link between baby loss and Post-Traumatic Stress Disorder (PTSD) and depression, which in some cases has resulted in suicide.
- 28. We recommend that psychological support for pre-24-week baby loss must focus on both parents (not just the mother). The importance of the partner's mental health as a potentially integral element of the mental wellbeing of a

- bereaved couple or family during and following baby loss, should be recognised and acknowledged more widely.
- 29. Current mental health provision for individuals following pre-24-week baby loss is insufficient and must be improved to ensure support is easily accessible for anybody who needs it.
- 30. All healthcare professionals caring for women and their partners who experience a baby loss must be made aware, through education and training of the psychological impact of baby loss and the increased risk of PTSD and suicide. This could be delivered via e-learning modules through the Workforce, Training and Education directorate of NHS England.
- 31. Where any healthcare professional believes an individual needs evidencebased psychological therapy, a referral must be made to the Perinatal Mental Health team. Confirmation that the referral has been received must be given.
- 32. When a GP or GP practice is informed that a patient has experienced a baby loss, a letter of support detailing baby loss support and counselling support organisations should be posted or emailed, if the patient has given consent for correspondence. This is to ensure that the patient knows that their loss has been formally acknowledged and that they have access to details of support organisations. A template is included in Annex G.

#### Pain Relief

- 33. The NIHR should commission research into pain management for pre-24week baby loss as our research has shown that patients are often left without suitable or sufficient pain relief.
- 34. The Royal Colleges of Obstetricians and Gynaecologists, Nursing, Midwives and GPs should develop resources and information to ensure support for healthcare professionals regarding use of analgesia and anti-emetics for anyone experiencing a pre-24-week baby loss.

#### Sensitive handling & storage of baby loss remains

- 35. We must have an enforceable guideline or regulation (in line with the Human Tissue Authority (HTA) guidance) surrounding the sensitive disposal of pre-24-week babies and baby loss remains, rather than guidance which is not always followed.
- 36. The NHS in partnership with Zoe and Sam, should develop and deliver an appropriate and sensitive receptacle to collect baby loss remains when a person miscarries.
- 37. The NHS in partnership with Zoe and Sam, should develop and deliver an appropriate, respectful container where baby loss remains may be stored following a miscarriage.
- 38. We are currently working to develop a 'Baby Loss Kit' called the 'CCC Kit' (Compassionate Clinical Care Kit), to be provided to women when a

miscarriage is expected or likely to take place in a home setting or in a clinical setting. The 'CCC kit' should comprise a receptacle and a container to collect and store the baby's remains, clear instructions for the clinician regarding how to explain the use of the kit to the woman (e.g. using patient-led language), clear instructions for the woman on what to do, what to expect, and should include emergency contact details. Ideally, the kit would also include a lanyard that a person could wear when accessing help or support in any clinical setting, so medical staff are aware of their previous or current loss. The 'CCC Kit' should be available from all NHS hospitals, GP practices, community health services, pharmacies, etc. The 'CCC Kit' should also be offered to people who are pregnant again following a previous loss.



- 39. EPAUs and A&E's should ensure that cold storage facilities (e.g. a dedicated refrigerator) are available to receive and store baby remains / pregnancy tissue 24/7, so that people aren't asked to store them in their home refrigerators.
- 40. Each Trust should offer a choice of personalised, individual or communal funeral services to all individuals who experience pre-24-week baby loss. All parents should be given the opportunity to attend their baby's funeral, whichever type of funeral they choose.

#### Palliative Care

- 41. Each Trust and ICS should establish and implement a clear clinical pathway (based on the British Association of Perinatal Medicine (BAPM) Guidelines<sup>3</sup>, <sup>4</sup> and the Together for Short Lives Perinatal Pathway for Babies with Palliative Care Needs<sup>5</sup>) for pre-24-week gestation babies born with signs of life that encourages professionals to work together across multidisciplinary teams and local services to provide sensitive parent-centred end of life care, enabling families to spend time with their baby, and create precious memories.
- 42. To reduce regional variations in neonatal death rates, all clinicians caring for women and babies born before 24-weeks gestation should be required to undertake training in the MBRRACE-UK (Mothers and Babies, Reducing Risk through Audit and Confidential Enquiries) national clinical guidance for the

'Determination of signs of life following spontaneous birth before 24+0 weeks of gestation'<sup>6</sup> where, following discussion with the parents, active survival-focused care is not appropriate'. Whilst this clinical guidance has been in place since 2020, there is still much confusion and inconsistency in its delivery.

#### Recurrent miscarriage

- 43. Working with the Royal Colleges, NHS England should develop standardised primary and secondary care clinical guidelines for pre-24-week baby loss, and the RCOG should further revise their Green-top Guidelines, so that local service providers and commissioners can update their local guidelines and service provision. The guidance should include:
  - Following the first loss, if individuals experience a pre-24-week baby loss, and request an appointment with their GP practice, a personcentred consultation should be offered to them. If appropriate or requested by the individual, during this appointment the individual's baby loss experience and future pregnancies should be discussed. Information about the impact on mental health and trauma that may ensue following a baby loss should be provided, and individuals should be advised that they can self-refer to NHS Talking Therapies. Clinicians should actively encourage this self-referral if they feel it would benefit the individual.
  - Following two losses, an appointment should be made for blood tests, including full blood count and thyroid function and other necessary investigations. Depending on the results of these tests, along with any other pre-existing or chronic physical or mental health conditions, referrals should be made to the relevant specialism.
  - Following a third baby loss a consultant-led appointment should be offered, at a specialist recurrent miscarriage centre where possible, so additional tests, including genetic testing, scanning, screening and treatment, may be offered.
  - The standardised primary and secondary care clinical guidelines should include flexibility to accommodate and prioritise differing factors such as advanced maternal age, infertility, recurrent loss, and other medical conditions.
- 44. Individuals recognised as high-risk for baby loss at their booking appointment or at any time during pregnancy should receive personalised care pathways, which may include a higher level of care and monitoring.
- 45. Specialist recurrent loss clinics should be developed in each region and offer a holistic service approach.
- 46. We recommend that an NHS-wide flag system should be implemented, so that pre-24-week baby loss can be highlighted on parent's patient notes. This will help healthcare professionals to be aware of any previous losses and

- assist them in providing a compassionate and sensitive care experience, without the individual having to repeatedly recount their story of loss. This should work in tandem with the lanyard recommendation (rec26).
- 47. The GMC should look to introduce credentials in Early Pregnancy Loss, and the RCOG and The British Society of Gynaecological Endoscopy (BSGA) should consider the opportunities to improve the specialist pathway in Early Pregnancy Loss.
- 48. The RCOG and The Association of Early Pregnancy Units (AEPU) should review training opportunities in Early Pregnancy Loss, Emergency Gynaecology, Prenatal Diagnosis and Recurrent Loss to ensure they meet the need for specialists in this area.
- 49. In a subsequent pregnancy, an early reassurance scan should be offered and the woman and her partner should be signposted by their midwife to appropriate services for ongoing emotional support and psychological support, to help manage anxiety levels.

#### **Ambulance Service**

50. There should be a review of guidance and training modules for all current and future ambulance staff, to ensure they are mentally equipped and appropriately trained in the management of pre-24-week baby loss. Where a training deficit is identified, this should be immediately addressed and protected time to attend additional training should be sanctioned.

#### Termination for Medical Reasons (TFMR) – Private providers

51. We understand that hospitals are limited in their capacity and workforce to perform surgical terminations and the majority of patients undergoing a TFMR are referred to the independent sector, therefore it is imperative that all providers have robust protocols and pathways in place for TFMR patients. The NHS and independent providers must have carefully coordinated pathways in place for women and their partners undergoing TFMR. Hospitals and independent service providers should seek to ensure that the partners of patients, or a person of their choice, undergoing a termination can attend the appointment at the clinic if this is what the patient requests. Excluding partners from what can be an equally distressing experience for both partners is unacceptable. Where possible, people experiencing a TFMR should not be cared for alongside patients who are choosing to end an unwanted pregnancy.

#### Sonography

52. Further oversight and governance of the profession of Sonography is essential to ensure that patients are offered safe and compassionate care. We are aware of the impending report from the Society of Sonographers that supports this. We therefore recommend that all sonographers should hold a UK qualification from the Consortium for the Accreditation of Sonographic

- Education, or overseas equivalent, as called for by the British Medical Ultrasound Society (BMUS).
- 53. All sonographers who may need to break unexpected bad news to parents should be required to undertake training on 'Consensus Guidelines on the Communication of Unexpected News via Ultrasound' and/or other courses to develop their skills.

#### Addressing disparities

- 54. The NIHR should commission additional research into why there is an increased risk of pre-24-week baby loss in women from Black, Asian and ethnic minority backgrounds and people from socio-economically deprived areas, and what may be done to minimise these risks.
- 55. National and local guidance should be developed to sensitively address the varying support needs of people who experience a pre-24-week baby loss resulting from alternative routes to parenthood, such as adoption and surrogacy.
- 56. We support the Law Commission's proposal on creating a new surrogacy pathway that will allow the intended parents to be the legal parents of the child from the moment of birth<sup>8</sup> and recommend that this also includes from the moment that baby loss occurs. This would eliminate the multiple obstacles faced by surrogate parents when arranging funeral/cremation services. Support for the intended parent and the surrogate mother should be offered.

#### Bereavement Care and Support

- 57. NHS England must increase capital investment to ensure adequate facilities are provided for bereaved parents. Bereavement suites, counselling rooms, and private spaces should be available to all families regardless of the baby's gestational age. Women and their partners should not be expected to receive unexpected bad news, discuss treatment options, or grieve in public spaces. Funding should be allocated for this.
- 58. NHS England must focus on recruiting and retaining more specialist gynaecology nurses and bereavement midwives, with equality of banding and pay. These roles are imperative to the delivery of safe and compassionate care to families experiencing baby loss, however due to them not being prioritised by all trusts, these roles are chronically underfunded and undervalued.
- 59. NHS England must ensure that specialist 'bereavement teams' are established in all hospital trusts to ensure that best practice is applied service wide. These teams should include the Bereavement Lead Midwife, Lead Gynaecology Nurse, Lead from EPAU, Lead from A&E (where applicable), Lead Chaplain, Lead of Neonatal, Lead of Paediatrics, the Trust Bereavement Services Lead, and the Mortuary Manager. The team should meet at least monthly to review cases, share learning and best practice and develop policies and procedures to create a forward-thinking maternity bereavement

- service for baby loss at all gestations. This team approach would ensure that regardless of in which department the loss occurs, the same level of emotional care and practical support is offered.
- 60. All Trusts must ensure they have a sufficient number of key staff who are fully trained (having undertaken the Perinatal PM Consent Training Programme or similar) in taking consent for post-mortem and the histological and genetic testing of early pregnancy loss remains, and that only these staff should be permitted to seek consent for a post-mortem. Additionally, it is essential that they are fully conversant with the current national and local consent processes relating to this, to ensure that all individuals considering these investigative procedures receive high quality information in a timely manner. All Trusts should monitor this training and compliance.

#### Baby Loss Certificate

61. In recognition of a life lost, the Government must ensure that an official certificate is available to anyone who requests one after experiencing any loss pre-24 weeks gestation. The certificate must be back datable with no cut-off point, so people with a historic loss may also access this long-requested recognition. The certificate must be available to anyone regardless of the type of loss they have experienced. Parents must have the option to be able to supply evidence of the loss, but this should not be mandatory. The wording on the certificate should be adaptable (including an option to add a baby's name), as it is vital that parents are able to choose the language they prefer. The certificate should be available as a download or as a hard copy. The certificate needs to be accessible by all, not just by people with access to a computer. This also needs to be available to both parents. To ensure the certificates remain credible, the applicant should be required to provide identity verification. The certificates will not be legal certificates but will be official government-issued ones, and should look official, rather than just commemorative, as it is crucial to families that they have official recognition of their loss. We will continue to partner with the Government to design and deliver this as quickly as possible.

#### Primary and Secondary Care Chaplaincy

- 62. All bereavement support services provided by each Trust and healthcare provider must ensure that the spiritual and cultural care needs of each patient are met and that hospital chaplaincy/pastoral services are offered to all individuals and their partners experiencing loss regardless of the type of loss or gestation.
- 63. A Primary Care Chaplaincy/Pastoral service has already been trialled in multiple areas including Birmingham, Dudley and across Scotland. GP's are able to socially prescribe listening services to patients<sup>9</sup>, <sup>10</sup>, <sup>11</sup>. This should be rolled out across all Primary Care nationally.

#### Patient Records, IT and Data

- 64. NHS England should issue guidance to all staff on using electronic patient records systems regarding the recording of pre-24-week baby loss. The data fields for recording such losses and generating notices to other electronic patient notes systems (e.g. GP patient records) must be made mandatory to prevent patients from being notified of outstanding maternity appointments and scans in error. We understand that this is a long-term objective rather than something that can be achieved both easily and quickly, but this must be prioritised in the current digital transformation programme.
- 65. People should be able to inform their GP that they are pregnant or that they have had a pre-24-week baby loss via apps such as MyNHS or MyGP or an alternative simple system. The system should trigger push notices to ensure that the patient has relevant information on pregnancy, baby loss, mental health care and support services.

#### Monitoring data

- 66. Whilst it would be beneficial to have published data of all pre-12-week baby loss, and we would fully support it if it could be accurately collected, our extensive investigation and consultations have shown that the current data collection systems are unable to deliver this. Furthermore, because the majority of baby loss occurs outside of primary and secondary care settings, and as it is the choice of the individual to disclose a baby loss, it would be impossible to gather any accurate data. Experts in NHS digital data collection systems have stated that even if it was possible to collect some data, the inconsistency of this information could be detrimental to the provision of care, as the data collected would not reflect the true scale of the problem. However, we recommend that the NHSE Transformation Directorate or NIHR should undertake research into the feasibility of pre-12-week data collection.
- 67. The DHSC should commission NHS England's Transformation Directorate to collate and publish monthly data on all mid-trimester loss (i.e.12-23 weeks + 6 days gestation). Monthly reports providing data that can be delivered from existing data sets, should be identified and published as soon as possible.

#### The Workplace

- 68. All organisations should update their HR policies and practices to adequately support staff who experience pre-24-week baby loss.
- 69. The NHS should be a leading example in offering excellent bereavement support and leave to staff who experience pre-24-week baby loss. We recommend that up to 10-days paid leave for the person who is pregnant and 5-days for the partner should be provided for any pre-24-week baby loss. A 'Fitness for Work' statement from a GP should not be required unless additional time off is required. This paid time off should not be used for 'sickness trigger' purposes. In addition, NHS employees (both the person experiencing the loss and their partner)should be offered paid time off for

- appointments linked to pregnancy or baby loss, and flexible working arrangements should be offered where possible.
- 70. Each Trust should offer reasonable bereavement leave and remove any restrictions limiting bereavement leave to 3 days per year.
- 71. Trusts should not group bereavement, sickness and parental leave in the same category.
- 72. The NHS must put adequate mental health support in place for all NHS staff.
- 73. The NHS must instruct Trusts to offer regular restorative clinical supervision sessions to staff who are working with loss on a daily basis, examples of which are bereavement midwives and antenatal screening midwives. Staff debriefing sessions should be set up by managers to support anyone affected by their work with pre-24-week baby loss, to help reduce stress and burnout.

#### Legal Age of Viability

At the start of this Review, in response to requests from MP's, we initially considered reviewing whether the legal age of viability should be reduced from 24 weeks to 20 or 22 weeks in line with some other countries. However, it was decided following an Advisory Panel meeting that this was outside of the scope of the Terms of Reference for this Review.

## **Chapter 1. Introduction**

- 1. Since the inception of the NHS in 1948, the policy of successive governments has been to improve the provision of maternity care so that women, their partners and their families are cared for in a way that meets their personal needs and choices while ensuring safe outcomes for both mothers and babies. This vision was reiterated in Better Births<sup>12</sup>, the report of the National Maternity Review, and in the National Maternity Safety Ambition to halve the rates of stillbirths, neonatal and maternal deaths and birth-related brain injuries by 2025<sup>13</sup>.
- 2. Improving the experience and safety of maternity care is right and extremely important, however, the attention of policymakers and the NHS has been predominantly focused on having a safe birth. Comparatively little policy attention has been directed towards improving the experience and outcomes throughout the early stages of pregnancy despite many families being affected by pre-24-week baby loss. The NHS is a world pioneer in early baby loss care with the development of EPAUs to provide dedicated services for pre-24-week baby loss. We are privileged to have some of the best clinicians and facilities providing world-class care and research, but there is still much more that needs to be done to improve the availability and accessibility of these services as well as care quality and experience for women and their partners.
- 3. For many years the poor and often substandard care of those who have experienced early baby loss has been reported in the press and to organisations such as the DHSC and the NHS. Disappointingly, this has resulted in very little change. Whilst there have been improvements in recent years in the care and support for those experiencing later losses, i.e. stillbirth and neonatal death, improvements in the care and support for individuals experiencing early loss are sadly lacking. In 2023, we are still hearing countless stories from people who are traumatised by their care experience and feel angry and dismayed at the total lack of compassion and support afforded to them during such a distressing time. We understand that these challenges that have existed for decades cannot be corrected overnight. However, with the appropriate resources and funding and a firm commitment from the Government to implement the recommendations contained within this report, the Government could revolutionise the clinical and emotional care of all those experiencing early baby loss.
- 4. The All-Party Parliamentary Group on Baby Loss (APPG) have made huge strides in raising awareness of baby loss and are committed to seeing compassionate care and excellent clinical practice across primary and secondary care. The APPG pushed for the creation and implementation of standardised bereavement care and this led to the DHSC commissioning the National Bereavement Care Pathway (NBCP)<sup>14</sup>.
- 5. The scale of the work involved in this review has been unparalleled. We have witnessed many NHS staff, community leaders, charities and others going above and beyond the call of duty to support and care for families tragically touched by loss whilst they themselves receive little or no support or resources to do so. Sadly however, over the past five years we have heard from many families who

- have been failed by a seemingly broken or ineffective system and are desperate to see a change.
- 6. Whilst pre-24-week loss is sadly common, it doesn't make it any less painful. The loss of a baby is a profound and life-changing event for many people. We owe it to all individuals in England whom each year will experience the loss of a baby, and to each baby that has died, to improve the care and support that is offered because each of these families deserves better care.
- 7. Due to Brexit, the Covid-19 pandemic and pressures within the DHSC, it has taken five years for this Review to reach completion; therefore, the recommendations in this document must be actioned without delay. Furthermore, we request to lead an independent working group to ensure the changes we have recommended are implemented and sustained.
- 8. The Covid-19 pandemic has also had a significant negative impact on access to GP, emergency and hospital-based services for individuals and their partners experiencing baby loss.
- 9. During the Review process, there have been some substantial developments in health care:
  - In April 2021, NHS England announced the development of new maternal mental health hubs to provide services to new, expectant, and bereaved mothers as part of the NHS Long-Term Plan. These clinics integrate maternity, reproductive health and psychological therapy for individuals experiencing mental health difficulties directly arising from, or related to, the maternity experience including for people who lose babies pre-24 weeks gestation<sup>15</sup>. 35 Maternal Mental Health Services are operational and accepting women onto caseloads. By March 2024, services will be rolled out across all 42 Integrated Care Systems.
  - Also, in April 2021, 'The Lancet' published 'Miscarriage Matters' a series
    of three papers which review the epidemiological, physical, psychological,
    and economic costs of early pregnancy loss. <sup>16</sup> The authors estimated the
    short-term national economic costs of miscarriage, associated with
    immediate costs to hospital and community health and social services, to
    be £471 million annually to the UK and suggested recommendations to
    improve outcomes.
  - NHS England published equity and equality guidance for local maternity systems in September 2021<sup>17</sup>. Local Maternity and Neonatal Systems (LMNS) began publishing their Equity and Equality plans in October 2022 which set out how the NHS will work in partnership to improve equity for women and babies and race equality for staff. The Maternity Consortium is undertaking work to implement these plans
  - In May 2022, the DHSC and NHS launched the Voluntary, Community and Social Enterprise (VCSE) Health and Wellbeing fund which aims to support women's reproductive wellbeing in the workplace<sup>18</sup>.

- In July 2022, DHSC published the first Women's Health Strategy for England<sup>19</sup> which included our proposal for introducing a 'National Certificate of Baby Loss'. Details on why we made this proposal and our recommendations for how the scheme should work are provided in Chapter 9. We were, however, extremely disappointed that the Women's Health Strategy contained little else relating to baby loss.
- 10. When visiting hospitals, units, and facilities, we witnessed exceptional care where doctors, nurses and staff went out of their way to offer excellent care and support. We heard from patients who felt forever indebted to the staff who had cared for them and considered them as 'their heroes' as they had literally held their hand through the worst time of their life. We saw passionate employees trying to change systems and make a lasting difference in their places of work. Sadly, we also witnessed and heard shocking accounts of poor patient experience. Common themes that were discussed with us included a lack of kindness and compassion, often seen as a result of poor training and education or due to time pressures, and a lack of respect or dignity given to the baby or pregnancy loss remains. At one hospital, we were horrified to learn that miscarried babies were regularly being disposed of in the clinical waste bin in A&E because the member of staff involved believed that this was the process. At another Trust, we discovered that babies up to 22 weeks were being sent from the gynaecology ward to the mortuary in placenta buckets. We heard alarming accounts, on more than one occasion from gynaecology, A&E and labour ward staff, (including cleaning staff and porters) who had accidentally discovered miscarried babies and babies with signs of life in bed pans or kidney dishes in the sluice. At one hospital, we were shocked to hear that people's race played a part in whether they were offered pain relief or not. Staff reported that they did not offer pain relief to black women 'as black people rarely complain, unlike white people'
- 11. Whilst we met many passionate doctors, nurses, midwives, and ultrasound staff, we also sadly witnessed teams who shared with us how burnt out, demotivated, and disillusioned they were with the system. Many expressed how they were constantly under extreme pressure and felt devalued and unsupported by management with little or no recognition of the emotional impact of the nature of their work or duties.
- 12. From the extensive work of this Review, and through our professional work, we know that these examples are sadly only the tip of the iceberg and it is essential that we see a radical change in the way that care is delivered to bereaved families and their babies. Through the work and findings of this Review, we now have an incredible opportunity to further improve the compassion, safety and quality of care for all families experiencing baby loss across England.

#### Scope of the review

- 13. The Review's Terms of Reference were published in March 2018 (Annex B). The purpose of the Review was to consider:
  - The impact on families of the current threshold of 24 weeks gestation before being able, formally, to register a baby loss if they so wish.

- Whether it would, on balance, be beneficial to look at legislative options to amend existing primary legislation to allow parents to register a baby loss if they so wish.
- Options to improve NHS gynaecology and maternity care practice for parents who experience a miscarriage and other causes of baby loss.
- 14. The Terms of Reference specifically set out that the Review would not consider changing the existing laws on abortion. They acknowledged, however that recommendations for improving care and support may be relevant to those who choose to terminate a much-wanted pregnancy, for example due to congenital anomalies. For the purposes of this Review, we interpreted 'pre-24-week baby loss' to include:
  - **Miscarriage at any gestation** the loss of a pregnancy during the first 23 weeks of gestation.
  - Ectopic pregnancy when a fertilised egg implants itself outside of the womb, usually in one of the fallopian tubes.
  - Molar pregnancy (hydatidiform mole) where an abnormal fertilised egg implants in the uterus. The fetus doesn't form properly in the womb and a baby doesn't develop. A mass of abnormal cells grows in the womb instead of a healthy fetus.
  - Termination for Medical Reasons (TFMR) & Termination of Pregnancy for Fetal Anomaly (TOPFA). For the purpose of this review we will use the acronym TFMR. The ending of pregnancy by removing an embryo or fetus by either medical (i.e. taking medication to end the pregnancy) or surgical (i.e. a surgical procedure to remove the pregnancy) means. Some people may choose to terminate a pregnancy if screening tests show that the baby has a serious abnormality.
  - Twins and higher multiple loss when one or more babies from a multiple pregnancy die during pregnancy or birth. In 2021, there were 8,470 pregnancies with multiple births, equivalent to 13.7 multiple births per 1,000 pregnancies in England and Wales<sup>20</sup>. Twin and multiple pregnancies, which are considered to be at higher risk of adverse outcomes compared to singleton pregnancies, have risen significantly over the past 30 years due to advances in reproductive medicine<sup>21</sup>. Intrauterine fetal deaths of one twin complicates up to 6% of all twin pregnancies.<sup>22</sup>

#### **Terminology**

15. Pre-24-week baby loss and bereavement is a highly personal and emotive subject. The words and language that people use to describe their experience, as well as the loss itself, will reflect their individual and unique feelings, values and beliefs, which may change over time. We have endeavoured to use language that is respectful and sensitive. In some cases, we have chosen to use particular words (e.g. 'baby' or 'parent'), but in so doing we recognise that they are not equally applicable for all people. For the purposes of this report:

- The term 'baby' is used to describe the child from the earliest stages of pregnancy. Many of the parents we work with and the vast majority of families we met with for this review identify their baby as an individual and they loved them from the moment they discovered that they were pregnant. It is important, however, to acknowledge that some people do not use the term 'baby' and will be more comfortable with medical terminology such as 'embryo', 'fetus' or 'pregnancy' and they may not find the term 'baby' to be appropriate in their situation.
- The terms 'woman' and 'women' are used throughout this report as this is the gender that most people who become pregnant and experience a baby loss identify as, although we understand that not all pregnant people self-identify as women and may prefer to be identified as 'birthing person'. Loss and grief are equal but unique experiences for everyone regardless of gender. Throughout our work on this Review, we have sought to understand the similarities and unique differences that all people experiencing baby loss go through and to make recommendations to improve the quality of care for all.
- The terms 'parents', 'mothers' and 'fathers' are used to refer to expectant or bereaved people who identify as the parents of the deceased baby including surrogate parents. Many people we work with consider themselves parents from the time they discover they are, or were, pregnant, while others will not.
- The term 'family' is used to refer to a group of people having a shared commitment to a mutual relationship. Some families may be legally related by blood, marriage, civil partnership, or adoption while other families choose not to demonstrate their commitment through religious or civil processes.
- The terms 'healthcare professional'(HCP) and 'clinician' are used to refer to someone, such as a nurse, midwife, therapist or doctor, who has qualifications in an area of very skilled health work and are regulated by a professional body such as the General Medical Council or the Nursing and Midwifery Council.
- The term 'staff' is used to denote all people, both clinical and non-clinical that a bereaved family may come into contact with while in a healthcare setting such as a GP surgery, a community clinic or a hospital.
- The term 'baby loss' is used throughout this report to refer to losses which occur in the first 24 weeks of pregnancy (although elsewhere it can be used to refer to all losses regardless of gestation). We appreciate that some individuals may prefer the term 'pregnancy loss' or other widely used terms, but following the parent consultations, it was determined that 'baby loss' was the preferred term for the majority of people.

### Chapter 2. How we carried out our work

- 16. We were invited to chair this Review because of our extensive knowledge, training, expertise in this area of healthcare, and also due to our personal lived experience of baby loss. The overarching principle for both of us has been to have the voice of people who have experienced pre-24-week baby loss at the very heart of this report and its recommendations. It has been imperative for us to meet and hear from people with various lived experience of baby loss, to better understand how the care they received has impacted on their physical and emotional well-being. Feedback on which elements of their care experience could have been improved as well as aspects of the care and support they received, which made a positive difference, were essential components to us being able to make the recommendations within this report.
- 17. It was equally important for us to meet with those who provide clinical care and emotional support in order to understand the intricacies and challenges of their jobs, the local and system-wide issues that might make it difficult to deliver high-quality and compassionate care, and the impacts on their own mental health and well-being.
- 18. In considering questions around certification of pre-24-week baby loss, we met with local authority registrars, the National Panel for Registration and officials at the General Registrar's Office. We also met virtually with officials in Florida (USA) and New South Wales (Australia) who introduced the first certificate of early baby loss schemes in their respective countries.
- 19. We conducted extensive meetings in England, Wales and Scotland, and with international colleagues, which included:
  - Visits to healthcare settings and meetings to consult with care
    providers about how baby loss is managed and observe current clinical
    practices. Locations included Emergency Services (i.e. 111, Ambulance
    and Accident and Emergency (A&E) Departments), Hospital Maternity and
    Gynaecology Wards, Mortuaries, Sonography Departments, and Early
    Pregnancy Assessment Units and visits to specialist clinics for miscarriage
    prevention and research.
  - Consultations, Focus Groups and Workshops:
    - i. **People with lived experience**: We convened focus groups in Birmingham, London, Manchester, and Coventry for people who had experienced early baby loss. In addition, we met with many individuals, couples and families on a one-to-one basis.
    - ii. Charities and Faith Groups: Parent support organisations and bereavement charities provide a critical role in providing information and support to pregnant women and bereaved parents. We invited several national bereavement care charities to a roundtable workshop to explore their experiences, challenges, and potential

- solutions. We also had one-to-one meetings with other charities and faith leaders.
- iii. **Healthcare professionals:** Through roundtable discussions, daylong hospital and clinic visits, and individual meetings we spoke to and shadowed healthcare professionals working in many different capacities, and geographical regions to understand the challenges they face and what changes they feel should be made to improve care. We also heard and witnessed examples of excellent practice.
- iv. Government, other National and Local Organisations and academics: These include but are not limited to the Royal College of Obstetricians and Gynaecologists, the Royal College or Midwives, the Royal College of Nursing, the Royal College of General Practitioners, NHS England, NHS Supply Chain, the Office for Health Improvement and Disparities, Health Education England (this is now the Workplace, Training and Education Directorate), the NHS Transformation Directorate, the Bereavement Midwives Forum, the Department of Health and Social Care, the General Registrar's Office, the National Panel for Registration, NHS Business Services Authority, and the All-Party Parliamentary Group for Baby Loss.
- Bereavement midwife survey and Forum: We carried out an online survey for bereavement midwives to gather information about their experiences and recommendations. We also attended National Bereavement Midwife Forum meetings and met with individual Bereavement Midwives.
- Academics: We met with clinical and non-clinical academics to learn about the latest research studies in physical and mental health care and bereavement care.
- **Desk-based research:** We carried out extensive literature reviews to gather information from qualitative and quantitative research on baby loss care and registration practices.
- 20. An Advisory Panel was established comprising representatives from professional clinical bodies, leading national bereavement charities, people with lived experience of pre-24-week loss, Registrars, interested Parliamentarians, and others. They met four times and reviewed a draft copy of the recommendations prior to publication.

# Chapter 3. Understanding the scale of pre-24-week baby loss

- 21. This chapter sets out the quantitative data that is currently available about pre-24 week baby loss and the impact on NHS services.
- 22. Baby loss is a tragic but sadly common adverse pregnancy outcome; however, it is not possible to know exactly how many pregnancies end before the 24<sup>th</sup> week of gestation. Complete data on the number of all of the types of early baby loss covered by this Review is, unfortunately, unavailable. We only have data on case numbers for births (Figure 1) and TFMR under Ground E (in which a termination may take place at any gestation if two doctors agree that 'there is a substantial risk that if the child were born it would suffer from such physical or mental abnormalities as to be seriously handicapped') (Figure 2).

Figure 1

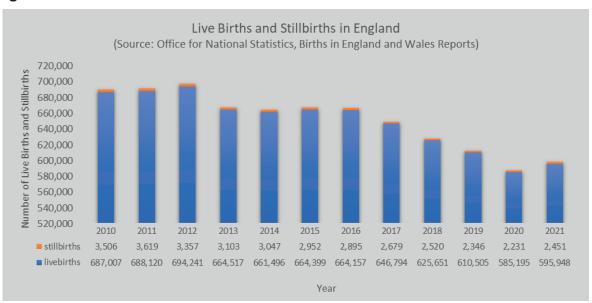
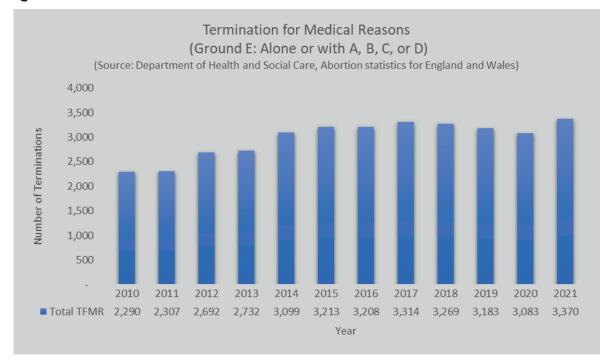


Figure 2



23. It has been estimated that around one in 80-90 pregnancies in the UK is an ectopic pregnancy<sup>23,24,25</sup>. Cases of 'miscarriage' are hard to quantify because some women who experience a miscarriage do not report this to a healthcare provider. For very early losses, women may not even be aware that a miscarriage is taking place and may assume the bleeding is a normal menstrual period. Recent studies have estimated the risk of miscarriage to range between 15%<sup>26</sup> -30%<sup>27</sup>. It is estimated that there are around 250,000 miscarriages in the UK each year<sup>28</sup> which, based on the number of births in each UK country, would equate to around 214,500 miscarriages in England each year. Molar pregnancies can also be hard to quantify. There are often no signs that a pregnancy is a molar pregnancy. It might be identified during the first pregnancy ultrasound scan at around 8 to 14 weeks. Some people only find out after their pregnancy ends with a miscarriage if the tissue is examined<sup>29</sup>. Twin and multiple pregnancies also pose a higher risk of loss, with the poorest outcomes for Black, African. Caribbean, Pakistani and Bangladeshi women, especially those from deprived areas30.

#### **Disparities**

24. There is an increased risk of loss for women from Black, Asian and ethnic minority groups. The Lancet series reported that Black women are at a 40% increased risk of experiencing a miscarriage<sup>31</sup>. Furthermore, people from low-income and deprived areas are also a greater risk of loss due to environmental and other factors. The charity, Five X More, are committed to highlighting and changing black maternal outcomes in the UK<sup>32</sup>. We need to see more research into the complex factors underpinning such disparities and more work across all ethnic minority groups and socio-economically disadvantaged groups to ensure disparities are addressed.

#### **Hospital Activity Data**

25. While we might not be able to know the true number of baby losses, data on hospital activity in England relating to these conditions is available from NHS England Hospital Episode Statistics (HES) and the NHS England Emergency Care Data Set. NHS England also publishes an annual report on maternity statistics for England which includes data on miscarriage and ectopic pregnancies that result in an NHS hospital stay. With this information, we can at least begin to build a picture of the numbers seeking care and the demand for NHS services.

#### Hospital Admissions

- 26. The numbers of miscarriages (ICD10<sup>33</sup> diagnostic code O03), ectopic pregnancies (diagnostic code O00), molar and other irregular pregnancies (diagnostic codes O01 and O02) which resulted in a hospital stay for the past twelve years are provided in Figure 3. Inpatient admissions for miscarriages have declined by about 22% from 43,005 in 2010-11 to 33,352 in 2021-22. Inpatient admissions also declined by about 33% for molar and other irregular pregnancies from 29,117 in 2010-11 to 18,855 in 2021-22. Inpatient admissions for ectopic pregnancies have remained relatively constant at an average of about 10,700 per year.
- 27. Most hospital admissions for pregnancy losses are classified as emergency admissions (Figure 4). On average between 2010-11 and 2021-22, 62% of miscarriage admissions, 86% of ectopic pregnancy admissions and 38% of admissions for molar and other irregular pregnancies were emergency admissions.

Figure 3

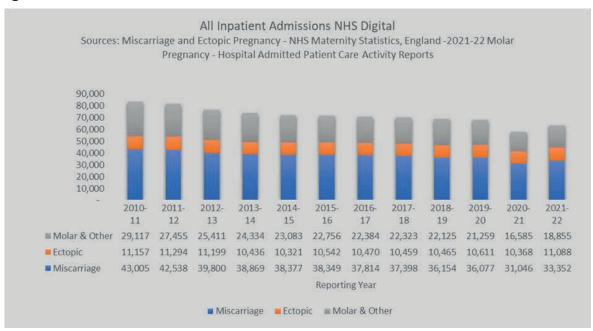
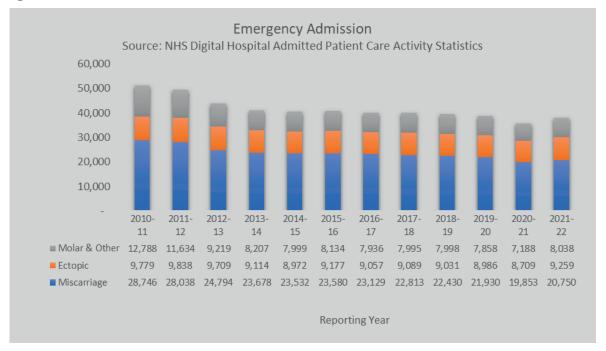


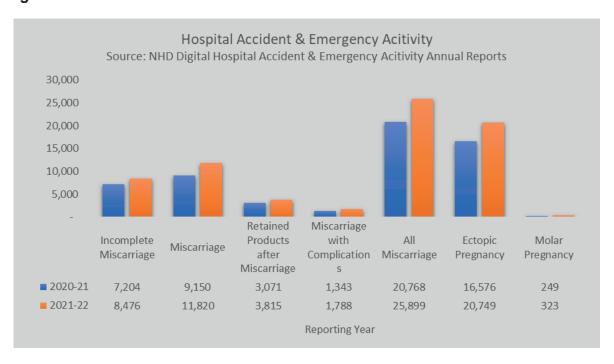
Figure 4



## Accident and Emergency

NHS England reports on A&E activity (i.e. A&E attendances in NHS hospitals, minor injury units and walk-in centres) since 2007-08 however until 2020-21, information on pre-24-week baby loss was included under the broad heading of 'obstetric conditions'. From 2020-21, this information has been provided for miscarriages, ectopic and molar pregnancies (Figure 5).

Figure 5



#### **Outpatient Attendances**

- 28. While inpatient admissions have declined, outpatient attendance data for miscarriage, ectopic and molar pregnancies show a significant increase between 2010-11 and 2021-22 (Figure 6). When we looked at the information on data quality, however, it was clear that many healthcare providers did not submit data on baby losses in the earlier years. Over the past 5 years, there have been on average around:
  - 4,000 outpatient attendances for miscarriages,
  - 844 for ectopic pregnancies, and
  - 4,072 for molar and other irregular pregnancies each year.

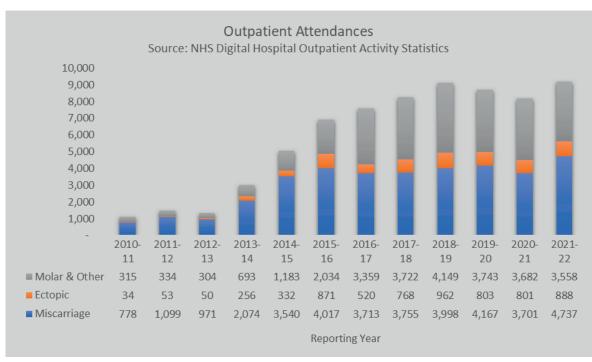


Figure 6

#### Impact of Covid-19

- 29. The Covid-19 pandemic significantly disrupted NHS services. NHS guidelines to prevent infection restricted access to in-person services unless absolutely necessary. For miscarriages, inpatient admissions and outpatient attendances decreased 14% and 11% respectively from 2019-20 to 2020-21. Inpatient and outpatient activity for molar and other irregular pregnancies also decreased in the first year of the pandemic, but there were no changes in inpatient or outpatient activity for those with an ectopic pregnancy.
- 30. The Covid-19 guidelines that prohibited an individual's partner from attending NHS settings could have influenced many decisions not to seek professional care while experiencing baby loss. Many people could not face going through such an experience alone. It was completely unacceptable for partners to be excluded

- from NHS care settings when they were also a parent and equally affected by the loss, and these restrictions should never be implemented in the future.
- 31. Unfortunately, pre-Covid-19 pandemic data on A&E attendances is not available. The data that is available shows a 25% increase in A&E attendances from 2020-21 to 2021-22 for both miscarriages and also ectopic pregnancies.

## Summary

- 32. The data that is currently available does not enable us to understand the overall scale of pre-24-week baby loss in England. This is especially the case for miscarriages, molar and other irregular pregnancies. Without this information, it is more complex to adequately provide the clinical services, emotional support, and the information that individuals experiencing loss require.
- 33. We have shown in this chapter that mid-trimester data on pre-24-week baby loss (i.e. losses occurring 12-23 weeks + 6 days gestation) is available in NHS datasets that record clinical care when losses occur in hospital. Information is also available from the Maternity Services Data Set which collects information during the pregnancy booking appointment on any previous losses less than 24 weeks and the discharge reasons from maternity services<sup>34</sup>. Discharge reasons include 'miscarriage' and 'termination of pregnancy less than 24 weeks. The reasons do not specifically include ectopic or molar pregnancies.
- 34. It is important to note that not all baby loss occurs in a hospital setting, in fact the majority do not. Some information on these cases is collected by the Ambulance Data Set which is currently in development and also via GP records where women may have informed their GP about a loss for which they did not seek NHS hospital care.

# **Chapter 4. Care for women and their partners**

- 35. When a pregnant woman books with a maternity service, their care pathway is clearly set out. They will have a named midwife who will coordinate their care based on their personal clinical needs and individual choices. They will be provided with information to help them understand their pathway and schedule of appointments and scans. They may be referred for some aspects of care to be provided by specialist doctors or midwives if there are concerns about their health or the health of their baby, but overall responsibility for their care will reside with the maternity service. In most cases maternity care ends around 10 days after birth when the individual and their baby/babies are discharged from maternity services to the care of their GPs and health visitors.
- 36. When a baby dies before 24 weeks gestation, the care pathway often disintegrates (Figure 7). Depending on the duration of the pregnancy and where they reside, a woman may no longer be able to receive care from their local maternity service. In an emergency, many people are unclear whether they should call 111, the ambulance service, or their GP or whether they should attend A&E or an EPAU. The change in pathway and having to navigate an unfamiliar system only serves to compound the misery and isolation for an individual experiencing loss.
- 37. It is important to add that those individuals experiencing early loss will not yet have booked with a midwife and entered onto the maternity pathway and will therefore also be unaware of how to access appropriate care and support. We need to see an immediate change to this.

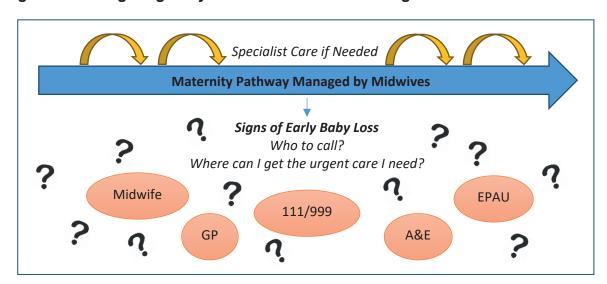


Figure 7 – Navigating baby loss services is confusing

## **Education and Information**

- 38. People experiencing pain and bleeding in early pregnancy will naturally be concerned and often distressed. This is not only because they are worried that something may be wrong but is often because they don't know who to call or what to expect when they do call. When this happens late at night or away from home, it can be particularly stressful.
- 39. From our extensive experience and from the feedback that we have received whilst conducting this Review, we have serious concerns around the lack of information and choices offered to individuals and their partners experiencing pre-24-week baby loss around what is likely to happen to them and to their baby. Some of the families we met with during this Review reported feeling uninformed, undermined and even patronised by healthcare staff. We are also concerned about the considerable, unwarranted variation that exists in the clinical and emotional care that is provided to people experiencing baby loss. This variation in care not only exists between different Trusts and other healthcare providers (e.g. GP practices and ambulance services) but more worryingly is how there can also often be a disparity with the level and quality of care provision within the same Trust or healthcare provider. This may be linked to the type of loss experienced (miscarriage, ectopic/molar pregnancy, TFMR), the gestation of the pregnancy, or the hospital department in which the loss occurs. A person having a mid-trimester miscarriage being cared for by a bereavement midwife with access to a bereavement suite is highly likely to have a very different experience of care compared to an individual having an early loss within an A&E department, within the same Trust.
- 40. It is essential that all people should have an awareness about the signs of baby loss and who to call when and if they have concerns at any time of the day or night. This awareness can be developed by being taught about miscarriage in school and through public health messaging.

#### Compulsory education about miscarriage

- 41. The DfE introduced compulsory Relationships, Health and Sex Education (RHSE) for secondary pupils in September 2020. The Statutory guidance for school leaders states that students should know 'the facts around pregnancy including miscarriage' by the end of secondary school<sup>35</sup>.
- 42. We reviewed some of the resources available to support teachers on the topic of miscarriage but we only found a few examples. Unfortunately, we did not consider any of these fit for purpose, as they mainly focussed on the physiology of miscarriage and did not include how to seek help from the NHS or what to expect. We therefore recommend the DfE must expand the current RHSE guidance for schools to cover all types of baby loss, not just miscarriage. The supporting teacher training modules should also include information on symptoms of baby loss, how to access care, and where to access support. While we understand teachers do not want to distress students, it is inappropriate to say that we do not educate people in case we upset them.

## Public health messaging

- 43. For too long, speaking about baby loss has been a taboo subject. This has to change if we want pregnant individuals and their partners to have confidence that they know what to do if they have any concerns about the pregnancy. NHS England should work with Trusts and their Maternity Voices Partnerships to review the quality and accessibility of information on pre-24-week baby loss, including what information should be given at the first antenatal visit and what to do and how to access services if there is pain and bleeding in pregnancy. This information should include a list of local NHS services and the care they can expect to receive, as well as emergency contact numbers and medical guidance on managing symptoms. People should know what to expect in advance. This information needs to be available in all languages, and in Easy Read and digital formats.
- 44. It is important that information on pre-24-week baby loss, is available to women and men before pregnancy. A simple and inexpensive way to achieve this would be for NHS England to commission the development of a poster on 'what to do if you have pain or bleeding during pregnancy' to be made available to GP practices, sexual health clinics, pharmacies, and Women's Health Hubs. The poster should include a QR code to link to more information and include space for details on how to contact local NHS services.
- 45. Information about pre-24-week baby loss on all NHS digital platforms should be improved. We recommend that we work in partnership with the NHS Transformation Directorate to undertake a review of the availability and accessibility of information on 'what to do if you have pain or bleeding in pregnancy' across all digital platforms including <a href="https://www.nhs.uk">www.nhs.uk</a>, NHS Apps and Maternity Notes Apps (e.g. BadgerNotes) and take steps to ensure information about baby loss is clear and easily accessible. This should include links to information on how to access baby loss care services 24/7 based on a woman's location and what care they can expect to receive.
- 46. We also recommend that pre-24-week baby loss support and advice lines that are available 24/7 should be established across ICS or other geographical regions for anyone experiencing baby loss. The advice lines will ideally be based in Trusts with access to clinicians so that appropriate advice and support can be offered immediately. Patients can then be referred to the most appropriate department for treatment and care at the most suitable time. Being given an appointment with an EPAU for the following day could save an individual a latenight trip to A&E. The CQC should monitor that Trusts have implemented these advice lines.

## **Early Pregnancy Assessment Units**

- 47. The healthcare professionals we spoke with uniformly agreed with our view that EPAUs should be the primary place where people experiencing a pre-24-week loss should be directed and that it must be made much easier to access these services at any time of the day or night than it is currently. EPAUs are specialist units that provide outpatient care for individuals with problems or concerns in early pregnancy. The UK are world leaders in developing this specialised model of care with the establishment of the first EPAU in 1991<sup>36</sup>.
- 48. EPAUs aim to provide comprehensive care to pregnant women, which includes clinical assessment, ultrasound and laboratory investigations, management planning, and support. They have been found to shorten the time taken to reach a correct diagnosis and a reduction in the number of hospital admissions for individuals with suspected early pregnancy complications<sup>37</sup>.
- 49. With regard to EPAU access, NICE guidelines on 'Ectopic pregnancy and miscarriage: diagnosis and initial management (NG126)<sup>38</sup>' state:
  - Regional services should be organised so that an early pregnancy assessment service is available 7 days a week for individuals with early pregnancy complications, where scanning can be carried out and decisions about management made.
  - Early pregnancy assessment services should accept self-referrals from individuals who have had 1 miscarriage or a previous ectopic or molar pregnancy.
  - All other individuals with pain and/or bleeding should be assessed by a healthcare professional (such as a GP, A&E doctor, midwife or nurse before referral to an early pregnancy assessment service).
- 50. We have identified 158 EPAUs in England (Figure 8) and we have reviewed the information provided about these services on their Trust websites (See Annex C). This information was hard to find and we acknowledge that it may not completely represent the current situation. The information can also be confusing because there is wide variation between hospitals (even within a single trust) in the criteria for individuals to receive EPAU care.

## Figure 8



#### EPAU opening hours and access criteria

- 51. Most of the EPAUs we identified follow the current NICE guidance and only see individuals if they have been referred by a healthcare professional such as a GP, midwife, or an A&E clinician unless they have a previous history of early baby loss. Some EPAUs do not require women to be referred by another healthcare professional but do require people to telephone and speak to a triage nurse who will advise on whether they should make an appointment with an EPAU or attend as a 'walk-in', attend A&E, or stay at home and speak to their GP, practice nurse or midwife.
- 52. Typically, people with pain and bleeding in early pregnancy are referred by midwives, GPs or NHS 111 to A&E services instead of an EPAU. This may be because most of the EPAUs we found are only open during normal working hours. Our analysis shows that only 109 of the 158 EPAUs in England publish information about their opening hours. Only seven units offer 24/7 access and a further 27 are open at least part time on weekends and some bank holidays (Figure 9). Most units are only open during business hours (50) or part time (25).
- 53. An appointment time in EPAU is standardly 20-minutes in length. During and since the pandemic, in some locations, appointment times were increased to 30 minutes. Whilst these longer appointments have remained in some EPAU's, others have since reverted back to 20-minutes. Both patients and clinicians have reported to us that 20-minutes is not long enough to offer good clinical care and emotional support, especially when they have to deliver unexpected bad news. Early in this Review, we heard that short appointment times were partly due to EPAUs not receiving payments under the previous maternity pathway payment tariff. We have since spoken with NHS England tariff policy leads who confirmed that the maternity payment system changed in 2022-23<sup>39</sup> and now EPAUs should receive payment for all activities they undertake.

- 54. The gestation of pregnancy also dictates where a person is directed to receive pre-24-week baby loss care and varies significantly depending on where they are in the country. Our research on EPAUs found that the maximum gestational age ranges from 12 to 22 weeks (see Figure 10). We found no gestational age information for 36 of the 158 services we reviewed. Of the EPAUs that did publish access criteria:
  - 13 limited access to 12 weeks of pregnancy,
  - 21 see individuals up to 14 weeks, and
  - most (40) see people up to 16 weeks. 37 units see people over 16 weeks
    of pregnancy including one which advises that it sees individuals up to 21
    weeks and one that see individuals up to 22 weeks.

Figure 9

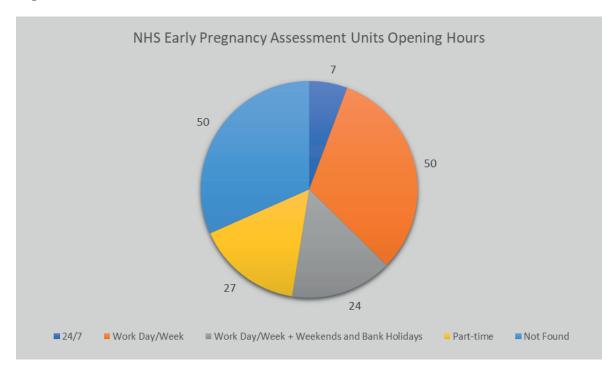
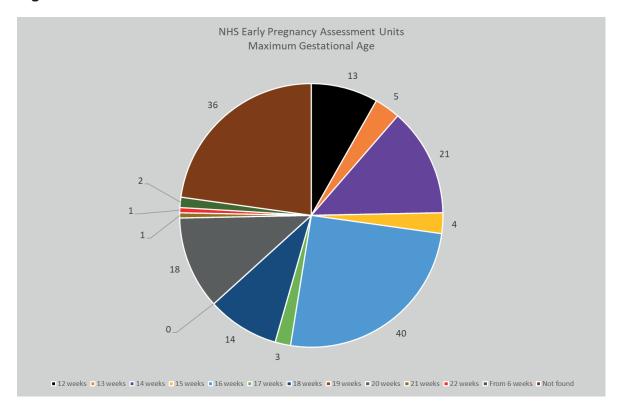


Figure 10



- 55. EPAUs offer extremely valuable care and support and all individuals who are in their first or second trimester of pregnancy should be able to access them more easily. We need to see more EPAUs open 24 hours a day, 7 days a week, although we understand that this would not be practical for every Trust or even every ICS in terms of both demand from women and clinical resources. Many people, however, told us that if they could, they would be prepared to travel longer distances from their homes in order to access an EPAU immediately rather than wait until the next day. This could be accomplished effectively and relatively inexpensively through baby loss services working in networks. We are not making specific recommendations about networking models, but instead, commissioners and service providers should co-develop networks with service users to reflect the needs of the communities they serve. We are, however, recommending that NHS England should develop guidance for Regional Teams and ICS on how EPAUs might work in networks so that women can access care 24/7 without needing a referral from another healthcare provider. In any area that is unable to offer 24/7 EPAU services, the ICB must ensure that the EPAU should operate a minimum of 9am-5pm opening hours Monday to Friday, and reduced hours on a weekend. The guidance should consider different models such as establishing central hubs and EPAUs based in community settings as well as in hospitals. These networks should support learning and the development of expertise across a geographical area.
- 56. Another relatively simple way in which the access to EPAU could be improved is by increasing the number of appointments made available to 111, and ambulance services. This practice is already in place in some parts of the country, but not everywhere. We recommend that NHS England should develop guidance for

- commissioners of 111 services and ambulance services that sets out how they should work with Trusts to contract appointments with EPAUs so that patients with early pregnancy complications who are medically stable can be sent directly to an EPAU when appropriate.
- 57. We recommend EPAU's should receive patients, who can be transferred safely, directly from the ambulance service during opening hours.
- 58. We further recommend that people should be able to self-refer to an EPAU with any pain or bleeding regardless of their gestation, or whether they have had any previous losses.
- 59. More research is needed into the ways in which EPAUs operate with a view to reducing variation and increasing accessibility. Most of the EPAUs follow the current NICE guidance and only see individuals if they have been referred by a healthcare professional such as a GP, midwife, or an A&E clinician unless they have a previous history of baby loss. This guidance has not been widely updated since 2012. In its most recent update of 'Ectopic pregnancy and miscarriage: diagnosis and initial management [NG126]' in November 2021<sup>40</sup>, NICE highlighted there has been very little good quality research on the effectiveness of EPAUs in improving physical and emotional health compared with services provided outside of a dedicated unit.
- 60. A recent large mixed-methods study, the VESPA study<sup>41</sup> found that consultant presence did not make any difference to the number of women admitted to hospital as emergencies and that nurse-led, low-volume EPAUs provided greater value for money and women were happier with the care that they received.
- 61. In June 2018, the Oxford EPAU relocated from the John Radcliffe Hospital to a community clinic creating the only community based EPAU that we found during our own audit of EPAUs<sup>42</sup>. A retrospective observational study of a single cohort of 2,920 patient episodes at the clinic over an 8-month period found that the development of a community EPAU improved services to allow care closer to home in an environment separate from maternity care. It also demonstrated that 'a community EPAU can deliver timely, good quality patient care, is safe, and a service valued by patients. We would encourage providers and commissioners to consider the development of more community EPAUs, perhaps as a part of a geographical network of EPAUs.
- 62. We recommend that the NIHR should commission additional research into EPAU working practices, accessibility, outcomes for women, and cost effectiveness (including prospects for new community EPAUs) drawing on the VESPA<sup>43</sup> and other studies.

## **Gynaecology Services**

- 63. Over the past decade, many hospitals have removed their gynaecology wards, deprioritising the need for the service. The impact of this is that women who require inpatient treatment are being cared for on mixed wards without private rooms or adequate facilities. One hospital reported to us that due to the gynaecology ward being removed, anyone experiencing pre-16-week baby loss is cared for on any ward with available space, including mixed wards with only one toilet available to all male and female patients.
- 64. The closure of these wards has led to highly trained gynaecology staff being redeployed or leaving the hospital altogether. The result of this is that patients are being treated on non-specialised wards and are more likely to be cared for by healthcare professionals without the specialist skills in bereavement care or gynaecology.
- 65. We recommend that there should be an immediate re-prioritising of gynaecology services by each Trust, including the ring-fencing of dedicated gynaecology beds co-located in one area, on female-only wards. Women experiencing pre-24-week baby loss or pregnancy complications should never be cared for in mixed wards with shared facilities. Furthermore, we believe that each ICB must provide a Gynaecology Day Assessment Unit that is accessible 7-days a week. This should be attached to or near to an EPAU and should be staffed by specialist gynaecology staff, who have received mandatory bereavement care training, and ideally have the ability to scan patients when necessary.

## **Ultrasound scanning**

66. EPAUs generally centre around the provision of an ultrasound scan to confirm the location and viability of a pregnancy. They may be carried out by sonographers, gynaecology nurses, midwives or doctors trained in ultrasonography. Every healthcare professional who conducts scans should be trained in delivering unexpected bad news.

#### Breaking unexpected news

- 67. How healthcare staff communicate with individuals experiencing a baby loss can have a dramatic impact on an individual's experience and recovery. Front line professionals such as A&E staff, GPs, paramedics, sonographers, gynaecology nurses, doctors and midwives receive limited training in effective communication and delivering unexpected, bad news. Often any training they receive takes place prior to qualifying. Additionally, constraints such as short appointment times and a lack of private spaces make it almost impossible for clinicians to provide the time and the personalised care a person and their partner experiencing baby loss require.
- 68. A key stage in the early baby loss experience is the time at which an individual receives unexpected confirmation that a baby loss has occurred, that a pregnancy is no longer viable, or a diagnosis of serious medical problems is discovered or suspected in the individual or baby. Receiving such unexpected and devastating news is a significant life event for many people and one that

- needs to be managed with competence and sensitivity by all staff who are involved along the care journey.
- 69. Academics have proposed various models to provide structure to the process of communicating unexpected and difficult news. Most recommend the delivery of a 'warning shot' before the main news is imparted. This is designed to prepare patients that bad news is coming and might run like this: "I'm afraid we have identified some concerning findings in your results" <sup>44</sup>. However, research led by Judith Johnson at the University of Leeds found that this warning shot is often not wanted in an ultrasound setting as parents have already received their warning shot from the sonographer's body language and facial expression<sup>45</sup>.

'if the news being delivered is that the baby has a disability, this kind of warning shot can be taken as a negative value judgement by the healthcare professional, which may offend the expectant parent and that parents instead prefer delivery of information to be direct, kind and in simple language.'

70. Johnson also recognised that while the UK is one of a few countries where sonographers routinely deliver information about unexpected findings, there is no recognised or standardised pre-qualification training for sonographers and ultrasound practitioners in communication<sup>46</sup>. Johnson subsequently led work to develop 'Consensus Guidelines on the Communication of Unexpected News via Ultrasound'<sup>47</sup>, which have been adopted by the British Medical Ultrasound Society (BMUS) and the Society and College of Radiographers (SCoR) in their guidelines for professional practice<sup>48</sup>. We recommend that this guideline should be incorporated into all sonography training curricula.

Lack of regulation for sonographers – private sonography clinics

- 71. We are very concerned about the lack of professional regulation for sonographers and the increasing use of private sonography clinics. New direct entry postgraduate and undergraduate ultrasound education programmes have enabled non-healthcare professionals to enter the sonographer workforce<sup>49</sup>. According to NHS Employers, many sonographers working in the UK are educated and trained abroad and there is no comparative list of ultrasound qualifications. Our position is that all sonographers working in England should be trained to a specific standard to ensure a high quality of patient care.
- 72. The CQC is responsible for regulating the services that private scanning companies provide, if they offer diagnostic procedures that use ultrasonography to examine the body. They have no role, however, in stipulating the qualifications for sonographers other than to recommend that people considering private ultrasound scans should check to see if their sonographer has completed a Consortium for the Accreditation of Sonographic Education (CASE) training course for sonographers that meets certain UK standards<sup>50</sup>. It is concerning that some baby scanning clinics try to avoid CQC registration by saying that they only offer souvenir scans, and this loophole should be closed.
- 73. The Royal College of Radiologists and the SCoR have set out 'Standards for the Provision of an Ultrasound Service'<sup>51</sup> and SCoR have also produced 'Competencies for ultrasound practice in private baby scan clinics'<sup>52</sup>, however, sonography is not a regulated profession. Qualified sonographers can register

- with the Health and Care Professions Council (HCPC) or the Register of Clinical Technologists (RCT), but registration is voluntary and not mandatory. Radiographers, nurses, midwives and doctors trained in sonography are regulated by their relevant professional bodies.
- 74. In 2021, the Government consulted on regulating healthcare professionals<sup>53</sup>. In the consultation outcome<sup>54</sup> the government committed to reform legislation framework for regulated health and care professionals across the UK. Current legislation will be changed to provide each regulator, including the Health and Care Professions Council (HCPC) which regulates radiographers, with greater autonomy to set out the details of their regulatory procedures in legislation that they themselves publish, called rules. We believe that further oversight and governance on the profession of Sonography is essential to ensure that all patients are offered safe and compassionate care, and the Society of Sonographers supports this. We therefore recommend that all sonographers should hold a UK qualification from the Consortium for the Accreditation of Sonographic Education or overseas equivalent, as called for by the BMUS.

## Written and verbal information

- 75. Individuals and, if appropriate, their partners and/or other family members should be given access to written and verbal information and allowed sufficient time to be able to make informed choices and prepare emotionally in relation to what to expect pre, during and post loss. We spoke to women who had been taken into the operating theatre, who had only been given minutes to decide what to do with their baby's remains. Being expected to make important decisions during acute times of distress, and not being given time to discuss this with their partner or other family members is not acceptable. It was also reported to us, that people commonly experience long periods of time with little or no information or contact with medical professionals. This often results in patients turning to the internet for information, information which isn't always accurate, creating unnecessary anxiety and distress, which is unacceptable, and easily avoidable.
- 76. A parent-led approach to terminology must be adopted. For example, some parents will refer to their loss as 'their baby' while others would feel more comfortable talking about 'the fetus'. Clinical terminology should be explained and when referring to the loss, staff should reflect the choice of language of that used by the individual and their partner. Following the parents' lead in difficult conversations shows compassion and respect for what the parents are experiencing. If there is any doubt, staff should simply ask what language is preferred. It is important to then document the parent's language choice in the patients records to ensure consistent use by all staff involved in the person's care. We therefore recommend that all healthcare professionals who may be in contact with anyone experiencing baby loss should have mandatory training on sensitive communication to ensure they are equipped to care for patients compassionately and are patient led in their terminology. This could be delivered via e-learning modules through the Workforce, Training and Education directorate of NHS England. Furthermore, the GMC and NMC should instruct all universities, medical schools and education providers to include this training in the syllabuses for all current and future students.

77. Information leaflets, bereavement support books and bereavement resources should be available to bereaved parents in all primary and secondary healthcare settings, in order that those affected by pre-24-week baby loss have immediate access to support and information and are educated about grief and trauma. This information should be available in all languages and in Easy Read and digital formats.

## Language barriers

- 78. For non-English speaking parents or those who are deaf, best practice dictates having a face to face interpreter available when delivering unexpected difficult news. It is not appropriate for a family member to translate news of this nature, and it certainly is not appropriate for a child to do this.<sup>55</sup> If, for whatever reason, a face to face interpreter is not available, all possible steps should be taken to ensure access to a phone or video interpreter is made available, such as via Language Line, or a similar service, which we witnessed in use in some of the hospitals we visited.
- 79. We are concerned at the lack of information leaflets and resources available to individuals whose first language is not English, and this needs to be rectified.

## Surroundings and environment

- 80. It is vital that a private space is offered to parents to receive unexpected and difficult news or following a baby loss. The importance of this was emphasised by parents, healthcare professionals and charities. This space could be used for multiple purposes including breaking unexpected and upsetting news, having sensitive conversations, waiting for follow-up care or further clinical consultations, spending time with the baby following delivery, or with family or others. Many parents with whom we spoke felt their distress had been compounded by the lack of a private space in which to grieve, and/or being surrounded by pregnant individuals and new-borns. These spaces should be funded by the NHS and not fall under the responsibility of charities or parents having to fundraise.
- 81. In addition to EPAUs, the care that people might receive may be in hospital gynaecology, maternity or A&E units. Care for confirmed mid-trimester losses (i.e. after the 12<sup>th</sup> and before the 24<sup>th</sup> completed week of pregnancy) are usually treated in hospital and managed either on a gynaecology ward or a maternity labour ward. Some Trusts do not have separate gynaecology wards and people experiencing a baby loss may be cared for on mixed general surgical wards or a maternity labour ward, which can be extremely distressing and highly inappropriate. During and after labour, it is vital that parents are offered a private room away from the sounds of labouring individuals and new-born babies. Some Trusts have a separate bereavement facility for loss at any gestation, but many do not. Each hospital maternity unit, EPAU and A&E department must provide suitable private spaces for patients experiencing pre-24-week loss, separate from public waiting areas. Access to appropriate bereavement delivery rooms for midtrimester loss and later loss must become the minimum level of facilities that all Trusts with maternity and gynaecology services should be providing.
- 82. People who are admitted through A&E should be transferred to a private area or be discharged home as quickly as possible. Individuals should be offered sanitary

items and clean clothing if actively bleeding and an appropriate receptacle for the baby (see Chapter 6 on Care for the Baby - 'CCC Kit') if a baby loss is imminent. Where private facilities are not available, staff should apologise and acknowledge how distressing this may be for parents. Healthcare professionals should always ensure that parents experiencing or facing the prospect of baby loss in the home setting are provided with adequate pain medication, a 'CCC kit' containing an appropriate receptacle in which to collect and store the baby or baby loss remains, and a named contact with an emergency number to call for support and advice with excessive bleeding, pain, or symptoms of an infection.

83. Many Trusts have 'bereavement suites' or 'dedicated bereavement care rooms', which are designated rooms within the Trust for this purpose. Sadly, there is considerable variation between Trusts in terms of provision of bereavement suites as well as who is able to access these. It is very rare for those experiencing an earlier baby loss to have access to these spaces. In addition, these rooms are typically located on maternity labour wards where care is provided to individuals who have had a stillbirth or neonatal death, which can be very distressing for those going through a pre-24 week loss and compound their grief.

## Pain management

- 84. The lack of adequate pain relief medication for individuals experiencing pre-24-week baby loss is a concern to us. Patients should be offered appropriate medication to help them manage their pain and other symptoms. The RCOG's early miscarriage patient information leaflet (PIL)<sup>56</sup> and the NICE guideline on Ectopic Pregnancy and Miscarriage (NG126)<sup>57</sup> both state that women should be offered pain relief and anti-sickness medication, however it only states the need to offer pain relief but doesn't state the type, dosage or period of time that individuals should receive it. We heard repeatedly from women that they were offered little or no pain relief or were given inadequate pain relief and this added to their distress. We found a significant variation in access to pain relief medication for individuals experiencing loss, some told us that they were offered only Paracetamol to medicate the pain, most told us that they were offered no pain relief at all.
- 85. The Mariposa Trust (Saying Goodbye) asked Consultant Pharmacist, Siobhan Abrahams, to develop a pain management plan for hospitals to use. The 'Guideline for Prescribing and Administration of Acute Pain Relief and Antiemetics in Pregnancy in the Emergency Department and Urgent Care' (See Annex D) brings together information to effectively manage pregnant women with acute pain and nausea/vomiting across the Emergency Department and Urgent Care. It covers the prescribing, monitoring and administration of medication to pregnant women in acute pain and has now been adopted at Northampton General Hospital and was shortlisted for a Healthcare Quality Improvement Partnership Audit Award. We suggest that the RCOG should consider endorsing this guideline or develop a new guideline that can be widely implemented.
- 86. Similarly, healthcare professionals stated to us that lactation suppressant drugs are not routinely offered to individuals experiencing pre-24-week baby loss and that no national guidelines exist to provide guidance to healthcare professionals

regarding when these drugs should be prescribed. We found that most trusts prescribe the lactation suppressant Cabergoline from 16 weeks gestation, however we heard from women who had experienced leaking breasts at much earlier gestations. The presence of breast milk for an individual experiencing baby loss may not have been anticipated and can be particularly distressing.

- 87. The NIHR should commission research into pain medication management for miscarriage at all gestations.
- 88. The Royal Colleges of Obstetricians and Gynaecologists, Nursing, Midwives and GPs should develop national guidance and resources on using analgesia and anti-emetics for all pre-24-week baby loss.

# **Chapter 5. Care for the baby**

89. No one can ever be prepared for the trauma of baby loss. The range of emotions is vast and is unique to each individual. It may be fair to say that most people start to imagine their future life as parents as soon as they discover that they are pregnant. When the pregnancy ends too soon, for whatever the reason, that dream of the future also ends. For the majority of parents, it will be essential that their baby's life, however brief, is recognised and that their baby/baby's remains are treated with dignity and respect regardless of the type of loss or the gestational age.

## **Twin and Multiple Pregnancies**

- 90. Twin and multiple pregnancies are considered to be at higher risk of adverse outcomes compared to singleton pregnancies, intrauterine fetal deaths of one twin complicates up to 6% of all twin pregnancies. Healthcare professionals should appreciate the complexity and mixed emotions of individuals who experience the loss of twins or a higher multiple pregnancy. When one baby dies with a surviving twin or higher order multiple, parents will require the same support through delivery and bereavement care. Adequate time should be given for multidisciplinary care planning and for parents to consider important birth choices, including memory making. An advanced care plan may be agreed between all parties for the most likely scenarios around birth. Parents may want to talk about the baby/babies that has/have died and to acknowledge that they were twins or a higher multiple pregnancy. Also, parents may not realise that it may be possible to take photographs of the babies together so this should be discussed and offered where appropriate. Later in life, the surviving twin may be interested to know about the sibling who died and to know that his or her twin was acknowledged and mourned.
- 91. Signposting the parents to The Twins Trust Bereavement Support Book<sup>58</sup> which has information to support parents experiencing multiple loss along their care pathway can be helpful. The Twins Trust have also created new guidance to support healthcare professionals caring for parents experiencing twin or higher multiple losses. The Butterfly Project has produced materials to educate staff so that the experience of families who have single fetal demise in a multiple pregnancy can be improved<sup>59</sup>. The Mariposa Trust (Saying Goodbye) also offer support for families who experience a twin or multiple loss.

## Respectful handling of baby remains

92. Whilst many of the parents we spoke to value the opportunity to spend time with their baby following delivery, this was not the case for everyone. Some parents had chosen not to see their baby, but many parents had simply not been given the opportunity to see or hold their baby after they were born at an early gestation. All too often, we heard from parents who having opted to see their baby were distressed at having their baby or baby's remains presented to them in a kidney dish, a bedpan, on a sanitary towel or even in a placenta bucket. One healthcare professional we spoke to on a hospital visit admitted to regularly throwing baby loss remains into a medical waste bin as they had not been

advised about the Trust's policies on sensitive disposal. We are aware that these are not isolated incidents and that similar practice is happening at many hospitals around the country. Baby or pregnancy loss remains should be treated with the utmost dignity and respect, and we have seen this is sadly often lacking with pre-24 weeks baby loss.

- 93. Under the Human Tissue Act 2004<sup>60</sup>, pregnancy remains are regarded as the tissue of the woman and consent is not required for their disposal. However, the HTA 'Guidance on the disposal of pregnancy remains following pregnancy loss or termination'<sup>61</sup> acknowledges that:
  - "...the particularly sensitive nature of this tissue means that the wishes of the woman, and her understanding of the disposal options open to her, are of paramount importance and should be respected and acted upon".
- 94. The RCN guidance on 'Managing the Disposal of Pregnancy Remains RCN guidance for nursing and midwifery practice' also states that:
  - 'If the woman requests that the remains be returned to her, these should be stored in an appropriate container (opaque, watertight and biodegradable) in a safe place and made available for collection by her or her representative.'
- 95. Despite the existence of guidance from the HTA as well as the RCN, we were told and we have witnessed that many staff are unclear of the processes involved in the management and sensitive disposal of pregnancy remains and in many cases are still disposing of babies and pregnancy loss tissue in clinical waste.
- 96. Given the significant variation in practice amongst Trusts (and in some cases within a single hospital), it is essential that there are robust clinical guidelines in place regarding how to respectfully handle, transport and manage baby loss remains and that all staff working in areas where baby loss occurs are familiar, through mandatory training and education with the policies and processes around sensitive disposal. We therefore recommend that an enforceable guideline or regulation around the sensitive disposal of all pregnancy loss tissue and babies, be introduced, rather than just guidance.

#### Appropriate receptacles and containers

97. We have huge concerns that there is a lack of a standardised, gestation appropriate NHS receptacle to collect and transport babies or baby loss remains to and within hospitals, in ambulances, GP surgeries, mortuaries, to funeral directors, to perinatal pathologists for post-mortem, or for parents to use to take their baby home. It is not acceptable to use bed pans, kidney dishes or sanitary towels to lay babies or pregnancy loss remains onto. If a miscarriage occurs out of working hours or away from a clinical setting (e.g. at home), the parents should not be asked to use a Tupperware container to store their baby or baby's remains in their household refrigerator until services re-open. We have heard time and time again about the negative and traumatic experiences of thousands of parents who have been advised to place their baby's remains in a plastic container, and to store it in their home fridge, due to the hospital department not being open or having no access to a fridge. This practice must stop. That is why we recommend that all primary and secondary care services should provide the 'CCC kit' and

- should ensure that cold storage facilities (e.g. a dedicated refrigerator) are available 24/7 to receive and store baby loss remains/pregnancy tissue.
- 98. In conversations with individuals from the Ambulance Service, we heard that due to the absence of a suitable container for loss, if the baby or baby loss remains are too small to fit into a car seat, parents are asked to carry their baby's remains (again in a kidney dish or on a sanitary pad) during the journey to hospital. If the parents object to this, a second ambulance may be required to transport the baby and remains. We recommend that the NHS in partnership with us, should develop and deliver an appropriate and sensitive receptacle to collect baby loss remains when a person miscarries. Furthermore, the NHS in partnership with us should develop and deliver an appropriate, respectful container where baby loss remains may be stored.
- 99. The lack of sensitive disposal, transportation and storage of babies and pregnancy loss remains is often due to a lack of resources on the part of Trusts. We learnt that there is a huge variation in resources, some of which are readily available from charities. Not every hospital has a cold-cot, Moses basket or tiny items of clothing, whilst others have an abundance of cold-cots and clothes kept in store cupboards.
- 100. All Trusts should have a cold cot and other resources (such as tiny items of clothing or appropriate receptacles such as cribs/Moses baskets) available. These should be accessible by all hospital departments including A&E and in EPAU's. One option we suggest is that Trusts should work together across ICS through their Local Maternity and Neonatal Networks or Regions to ensure a fairer sharing of this vital equipment especially for those hospitals that have limited resources. Many Trusts rely solely on charities to provide cold cots and other baby items, which reinforces the message that the NHS does not prioritise pre-24-week baby loss.
- 101. We recommend the development of a 'Baby Loss Kit' that is available through the NHS and can be given to parents if there is any risk of a miscarriage. We are currently working with the NHS to create such a kit that we are calling a 'Compassionate Clinical Care' Kit ('CCC Kit'). The kit will comprise:
  - A receptacle designed for women to deliver their baby into rather than
    delivering into a toilet or a bed pan. Ideally, this device would comprise a
    sieve that can be fitted over a toilet seat to retain the baby and placenta
    while allowing fluids to pass through.
  - A suitable and sensitively designed container in which to place the baby or pregnancy loss remains following delivery. This container could also potentially serve as a coffin for the cremation or burial of the remains.
  - Clear instructions for the clinician on how to explain the kit to women (e.g. using patient-led language.)
  - Clear instructions for the woman on what to do, what to expect, and emergency contact details.

 Ideally the kit would also include a lanyard that a person could wear when accessing help or support in any clinical setting in order that medical staff are aware of their previous or current loss.

The 'CCC Kit' should be made available to NHS hospitals, GP practices, ambulances, community health services, and pharmacies, etc. The kit should also be offered to people who are pregnant again following a previous loss.

## Signs of life

- 102. Studies in England <sup>63</sup> and internationally<sup>64</sup> identified wide variations in the percentage of births at 22 weeks + 0days to 23weeks + 6 days of gestational age registered as live births. Amongst Trusts in England, in 2012, this ranged from 20% to 80%. This range is unlikely to reflect a real variation in live births between areas and is more likely to suggest that there is variation in the way that different trusts recognise signs of life in very early premature births and therefore ultimately in the way that they are reported.
- 103. This level of variation not only has consequences for the reliability of data regarding neonatal deaths but also has significant financial and emotional impacts on many parents. This is because if a baby is born before 24 weeks gestation, the parents are only legally entitled to statutory parental bereavement leave and pay if the baby is born alive<sup>65</sup>.
- 104. A further complication is that within the UK, there is no statutory definition of live birth. Although a stillbirth has been defined in the Births and Deaths Registration Act 1953 (as amended by the Stillbirth (Definition) Act 1992<sup>66</sup>, section 115), it states only that a stillbirth is
  - "...a child which has issued forth from its mother after the 24<sup>th</sup> week of pregnancy and which did not at any time after being completely expelled from its mother breathe or show any other signs of life."

This does not make clear what constitutes 'any other signs of life'.

British Association of Perinatal Medicine Frameworks of Practice on Extreme Preterm Birth

105. The British Association of Perinatal Medicine (BAPM) has published two frameworks for practice documents in recent years: 'Perinatal management of extreme preterm birth before 27 weeks of gestation'<sup>67</sup> (October 2019) and Prehospital management of the baby born at extreme preterm gestation'<sup>68</sup> (February 2022). These frameworks provide clear guidelines for active survival-focused care in new-born babies. However, many doctors, nurses, midwives or paramedics will seldom be involved in caring for parents experiencing loss at the very borders of viability. According to MBRRACE-UK perinatal mortality data (2016-2019)<sup>69</sup>, an average of 1,035 babies were born at 22-23 weeks gestation per year. An average of 514 per year were live births of which an average 155 survived for at least 28 days. Many healthcare professionals, therefore, may experience difficulty in establishing what constitutes signs of life in such a preterm baby.

- 106. In 2020, MBRRACE-UK published new national guidance to support healthcare professionals in the assessment and documentation of signs of life in extremely preterm births, 'National clinical guidance for the determination of signs of life following spontaneous birth before 24 weeks + 0 days of gestation where, following discussion with the parents, active survival-focused care is not appropriate<sup>70</sup>. Crucially, both this guidance and the BAPM guidance emphasise how effective communication can reduce the impact of trauma on parents, both in the short and longer term and the importance of sensitive conversations about potential signs of life and advance care planning, involving parents and taking into consideration their wishes for end of life care.
- 107. We recommend that all clinicians caring for women and their babies born before 24 weeks gestation should be required to undertake training in the assessment of signs of life in extremely preterm births as set out in the 'National clinical guidance for the determination of signs of life following spontaneous birth before 24 weeks + 0 days of gestation where, following discussion with the parents, active survival-focused care is not appropriate' guidance. There is information and guidance and support videos available to support health care professionals in understanding and implementing this. This important guidance is due to be reviewed in November 2023 at which time we suggest that MBRRACE-UK undertake an assessment of how widely this guidance has been implemented, as we have seen that there is still much confusion and inconsistency in its delivery.

#### Palliative care

- 108. We met with one couple, who shared their harrowing experience of midtrimester loss with us. They spoke of their concerns about clinicians' confusion in recognising and managing signs of life in babies born before the legal age of viability, and the importance of providing coordinated, compassionate end of life care for these babies (See Annex E). Additionally, we heard disturbing accounts from staff working on Gynaecology wards and A&E who have been shocked to discover pre-viable babies with signs of life left to die alone in bed pans in the sluice.
- 109. The experience of the couple above is echoed by many families across the country whose babies have been born at the very borders of viability and have faced similar situations due to the ambiguity and lack of training around recognising and managing signs of life at delivery, decision making and providing palliative care.
- 110. If there is a possibility that a baby may be born alive, the parents should be sensitively advised by an experienced senior member of the health care team regarding the care that their baby may receive. A compassionate discussion around palliative and end of life care should take place in order that the parents' expectations are managed in a sensitive but realistic way. An advance care plan should be made with parental involvement. This should be documented and shared with the multi-disciplinary team. Parents should always be sensitively advised regarding what to expect following delivery and what may be possible in terms of spending time with their baby and memory making. Where the baby may be born with signs of life following a TFMR, it is vitally important that staff

recognise the mixed emotions of the parents and that the parents and the baby are offered the same level of bereavement care as with other types of loss. Every individual should be offered emotional support and given the details of NHS and third sector support.

- 111. We have reviewed a number of palliative care pathways for babies developed by local NHS services. Examples of best practice include the BAPM guidelines and 'The Perinatal Pathway for Babies with Palliative Care Needs'<sup>71</sup> developed by a team including the National Lead Nurse for Neonatal Palliative Care, Alex Mancini-Smith, and the charity Together for Short Lives. These pathways provide an approach that encourages professionals to work together across multidisciplinary teams and local services to provide sensitive parent-centred care, enabling families to spend time with their baby, bonding and creating memories.
- 112. NICE has found that 'there is little evidence regarding the experience families have of the death of a baby with or without specific support from a perinatal palliative care team. Individual case reports on family experience are very positive about perinatal palliative care, but published evidence is scarce'<sup>72</sup>.
- 113. Parents of babies born with persistent signs of life should be made aware that their baby will be classified as a neonatal death and the birth and death will need to be registered. Parents should be given advice on how and where to do this, and the timescales involved. Parents should also be advised regarding the potential for certain neonatal deaths of babies born before 24 weeks gestation including TFMR to be reported to the coroner. The Chief Coroner issued 'Guidance No.45 Stillbirth, and Live Birth Following Termination of Pregnancy'<sup>73</sup> in February 2023 to:

'help coroners understand and apply the current law relating to stillbirth, and live birth following termination of pregnancy, to promote consistency in the scrutiny of unnatural neonatal deaths.'

#### Bereavement care

- 114. Bereavement care relates to the 'formalised care and support given to benefit a bereaved individual, to help him or her deal with the emotional and practical problems following the loss of a loved one'.<sup>74</sup> Every person's bereavement experience will be different. For some people, unresolved grief can lead to serious mental health difficulties and is a risk factor for suicide<sup>75</sup> (we discuss this further in Chapter 7). Good bereavement care will be personalised and responsive to the person experiencing grief.
- 115. In addition to ensuring that communication and the clinical care provided to parents is sensitive and of high quality, providing parents and their families with emotional and practical support following baby loss is a fundamental part of offering best care. We found that a significant variation regarding the level and quality of bereavement care provided to parents experiencing pre-24-week baby loss exists in England with many services simply sign-posting parents to counselling and support services provided by charities or other organisations. Our view is that the NHS should address this unwarranted variation in

bereavement care provision and take responsibility for delivering high-quality and consistent bereavement care and support.

- 116. A huge issue for women experiencing baby loss is the setting of 'gestational thresholds' which may permit or restrict an individual's access to different types of service provision. These thresholds vary from Trust to Trust. This problem is further compounded by the fact that, traditionally, bereavement care following baby loss tends to take place in a maternity unit and often is only made available to bereaved parents who have experienced baby loss at later gestations. We heard repeated accounts from parents, about how pre-24-week baby loss is often treated more as a clinical incident rather than the death of a much-wanted baby.
- 117. Specialist Bereavement Midwives generally have overall responsibility for the provision of care, support and practical advice for women and their families experiencing later baby loss. They are typically assigned to work in maternity departments, as EPAU, Urgent Care and Gynaecology often sit outside of maternity services. Women experiencing pre-24-week loss are therefore less likely to be seen by a bereavement midwife and are more likely to be cared for by someone without the appropriate training or specialist skills. The National Bereavement Care Pathway (NBCP) sets out specific standards of care and guidance on pathways for miscarriage, ectopic, molar pregnancy and TFMR. This has been adopted in part or fully by 113 Trusts in England. Whether a trust wants to become part of this collaborative initiative or create their own localised bereavement care pathway, an effective system should be put in place and regularly monitored and audited to ensure consistency of compassionate care.
- 118. As part of this Review we attended the National Bereavement Midwife Forum which is a quarterly meeting where bereavement midwives from across the UK join together to network and share best practice in a supportive setting. Some of the specific concerns they told us were:
  - A 'postcode lottery' currently exists in bereavement care in gynaecology and maternity services and there is a huge variation in the bereavement midwife role. There is no standardised job description and there is an unwarranted variation in grading, pay scales, roles and responsibilities.
  - Each hospital decides how many hours are assigned to bereavement care.
     Some Bereavement Midwives practice clinically, as well as offering bereavement support, whilst others purely offer a support service. This variation in role, hours, and pay among Trusts was felt to be a real issue.
  - There is no standardised post graduate training or education programme for Bereavement Midwives or guidance around the role or level of care delivery expected of them.
  - They reported that they often had to undertake training in their own time, and at their own financial cost.
  - Many Bereavement Midwives felt that their hospital trusts did not place much value on their role and that management in particular did not have a grasp of the vast remit and responsibilities of their position. They reported that they

were regularly 'pulled' to work clinically and made to feel that that they were offering 'tea and sympathy' as opposed to being considered specialist health care professionals offering a vital lifeline to bereaved parents.

- 119. High quality bereavement care and support should be accessible to all parents experiencing loss, wherever they are cared for and whatever the gestation or type of loss. Support should also be offered to siblings and other family members if required. Our recommendations for improving bereavement care for families experiencing pre-24-week baby loss are as follows:
  - NHS England must focus on recruiting and retaining more specialist gynaecology nurses and bereavement midwives, with equality of banding and pay. These roles are imperative to supporting families experiencing baby loss, however due to not being prioritised by all trusts, these roles are chronically underfunded and undervalued.
  - NHS England must ensure that specialist 'bereavement teams' are established in all hospital trusts to ensure that best practice is applied service wide. These teams should include the Bereavement Lead Midwife, Lead Gynaecology Nurse, Lead from EPAU, Lead from A&E (where applicable), Lead Chaplain, Lead for Neonatal, Lead for Paediatrics, the Trust Bereavement Services Lead, and the Mortuary Manager. The team should meet at least monthly to review cases, share learning and best practice and develop policies and procedures to create a forward-thinking maternity bereavement service for baby loss at all gestations. This team approach would ensure that regardless of in which department the loss occurs, and regardless of when there are individual staff absences, a seamless level of emotional care and practical support can be offered.
  - NHS England should increase the current investment in NHS staff training in order that all health care professionals working in areas where loss occurs can undertake mandatory annual training and education in bereavement care. This training must include pre-24-week baby loss and staff must be given protected time in order to access the training during work hours.
  - Training and education in managing and supporting families who experience baby loss at all gestations should be included in the undergraduate and postgraduate training specifications for all clinicians, including midwives, nurses, doctors, sonographers, paramedics and also for healthcare support workers.
  - NHS England must increase capital investment to ensure adequate facilities
    are available for all bereaved parents. Bereavement suites, counselling
    rooms, and private spaces should be available to all families regardless of the
    baby's gestational age. Women and their partners should not be expected to
    receive unexpected bad news, discuss treatment options, or grieve in public
    spaces.

#### Memory making

120. Many parents that we spoke to held the view that creating tangible memories of their baby/babies was a vital part of their grieving process. Memory boxes, hand and footprints and photographs of the baby/babies were said to be particularly valuable. Many of these items are donated to Trusts and healthcare

providers by charities (many of which are led by bereaved parents who have themselves experienced a baby loss). This seems to be one of the very few areas of the NHS that relies on third parties and charities to fulfil vital elements of care.

- 121. It is essential that parents are offered genuine choices regarding memory making. Parents need to be given sufficient time in order to reflect on the information they are given and to make decisions regarding what they would like to do. While it is important that parents who have declined previous offers are not asked repeatedly, it is imperative that parents are made aware that they are able to change their minds, what the timescales regarding this are and who they should contact if this happens.
- 122. Whilst it is important to be sensitive and flexible to the parents' wishes around memory making, the condition, size and the gestation of the baby or pregnancy baby loss remains should be considered. If for example, where there is an identifiable body and the baby is severely macerated, is extremely fragile or has a visible abnormality it should be sensitively explained to the parents by an experienced member of staff exactly what will be and what is unlikely to be possible in terms of creating memories. If the parents do not wish to see their baby or pregnancy loss remains, their decision should be respected, however it may be possible to conceal macerated areas or a visible abnormality by dressing or wrapping the baby and this option should be explained and offered to the parents.
- 123. It is important that whatever the gestation, the baby should be dressed wherever possible or wrapped and presented to the parents in a dignified and respectful manner. Tiny items of clothing, pouches and cribs to lay miscarried babies and pregnancy loss remains in, are available free of charge from many baby loss charities. All hospitals and health care providers should ensure that these resources are available for all health care professionals caring for families experiencing loss to use. As mentioned earlier in this report, it is never appropriate to present a baby or pregnancy loss remains to parents in a kidney dish/specimen container, on a sanitary towel or in a bedpan.
- 124. Where there is no identifiable body, it may not always be possible for the parents to see the pregnancy loss remains, particularly for those women who have experienced a loss in very early pregnancy. Staff should approach this situation sensitively with parents and explore other ways of memory making or commemorating their loss, such as attending a service of baby loss, planting a tree, including their baby's name in a book of remembrance and requesting one of the new government issued baby loss certificates.

## Post-mortem and investigations

125. All Trusts must ensure they have a sufficient number of staff who are trained in taking consent for post-mortem, in line with current national and local post-mortem consent processes. The Perinatal Post-Mortem Consent Programme eLearning training, created by Dr Asha Shenvi and Jo Cookson is readily available and easily accessible<sup>76</sup>. All HCPs seeking consent for post-mortem should be required to undertake this training, and all Trusts must monitor

- compliance and training around this. This will ensure that all individuals considering a post-mortem receive the information they need to make an informed choice about post-mortem in a timely manner.
- 126. Where a post-mortem examination is requested, sufficient time needs to be allowed for seeking consent. The discussion around post-mortem examination should take place in a private, uninterrupted space and should include a detailed conversation regarding all aspects of the post-mortem process, including the timescales for the return of the baby's body and when to expect the results of the post-mortem to be available. In the absence of a post-mortem, fetal karyotyping (performed using fetal tissue to evaluate any chromosomal abnormalities), may be offered to parents to identify the baby's gender and to identify other potential genetic conditions.
- 127. Placental histology (i.e. an examination of the structure of the placenta) may reveal findings such as undiagnosed autoimmune conditions that have implications for future pregnancies such as recurrent miscarriage. It is crucial, therefore that following a baby loss all parents are given information regarding placental histology where appropriate.
- 128. Where the death of a baby has been referred to the coroner, the parents should be sensitively advised that the coroner may request a mandatory postmortem. The coroner's officer will be able to advise the parents of the process that this will follow. Parents should also be advised regarding the potential for certain neonatal deaths of babies born before 24 weeks gestation including TFMR to be reported to the coroner.
- 129. We heard from clinicians that there is currently a national shortage of perinatal pathologists resulting in the centralisation of perinatal pathology services. The impact of this is that many babies will need to be transferred from the place of delivery to the nearest regional pathology centre which is often many miles away. Depending on local service agreements, post-mortem examinations are often gestation related and only available for losses from 16 weeks gestation and above, thus excluding early gestation losses. Parents should be offered the option to pay privately for this procedure if it is not available to them through their local trust. It is essential that there is an increased investment in this vital service and that the recruitment and training of perinatal pathologists is prioritised, as the current wait times have a huge and detrimental impact on families, including influencing their decision on whether or not to consent to a post-mortem examination.

## **Funerals, Burials, Cremations**

130. Many parents and families who have experienced baby loss appreciate and value the opportunity to hold or to attend cultural and/or religious ceremonies and/or rituals, such as a blessing, a funeral, a remembrance service, or entering their baby's name in a book of remembrance. Where appropriate, spiritual care, religious ceremonies or services (offered by the hospital and third parties) should be offered to be eaved parents and families and cultural sensitivities should be carefully observed and respected by all medical professionals involved.

- 131. Whilst there is no legal requirement to bury or cremate pre-24-week baby loss remains, the HTA advise that:
  - 'Cremation and burial should always be available options for the disposal of pregnancy remains, regardless of whether or not there is discernible fetal tissue. Sensitive incineration, separate from clinical waste, may be used where the woman makes this choice or does not want to be involved in the decision and the establishment considers this the most appropriate method of disposal.'
- 132. It is imperative that bereaved parents are offered genuine choices around the funeral/sensitive disposal options for their baby or pregnancy loss remains. They should not be persuaded to give certain answers, by being asked leading questions. We have heard from many parents who, when they were being asked if they would like the hospital to dispose of their baby, felt unclear about what was being asked of them. Some reported that the way in which they were asked implied that there was a right answer and a wrong answer. One example of this is that a doctor said to a patient 'We standardly dispose of all babies in a sensitive way, is that ok with you?' The patient felt uncomfortable going against the 'norm' so agreed and replied, 'yes that's fine'. It is vital that parents are offered all options and given adequate time to make the most appropriate decision for them and their family.

# Chapter 6. After the loss

- 133. It is essential that all individuals and couples have follow-up care available to them and have access to support following pre-24-week baby loss. We are aware that follow-up appointments for pre-24-week baby loss are not routinely offered, however this is a vital component in next pregnancy planning and should be available to all individuals who request it. A follow-up appointment with a consultant must be offered to all bereaved parents awaiting results where there has been a post-mortem or other investigations such as genetic testing or placental histology. Where possible, the appointment should take place in a private space away from pregnant women and new-borns. There should be sufficient time allowed for the parents to ask any questions they have regarding their care and their emotional well-being should be discussed.
- 134. A very high proportion of baby loss occurs in the community and often happens prior to the booking appointment with a community midwife. In these cases, if a person seeks aftercare following baby loss it should be provided by a GP or practice nurse. Improved follow-up care could reduce or prevent many complications, such as retained pregnancy tissue which can lead to infection and haemorrhage, problems in a subsequent pregnancy and undiagnosed mental health issues such as PTSD.

# Post-loss information sharing with parents and between healthcare professionals

- 135. Many parents told us that they were not able to absorb the information given to them by a healthcare professional immediately following their loss. In view of this, best practice would necessitate a variety of methods for providing information across the multi-disciplinary system.
  - Bereaved parents told us that they valued being given written information that they could take home with them and refer to after leaving the hospital or healthcare setting.
  - The hospital bereavement team or a GP could send supplementary
    information to bereaved parents via post, e-mail or via the MyNHS or
    MyGP app. We heard of an example of best practice from a group of GPs
    in Leeds who have piloted sending a personalised letter of condolence and
    acknowledgement of loss to parents, including a list of national and local
    counselling and support organisations. We would like to see this happen
    nationally.
- 136. People are often cared for in more than one setting during and after a baby loss. It is essential therefore that their physical and mental health history is clearly communicated across all appropriate care teams. Clear communication across hospital departments and to the primary care team is essential, not only for the physical safety of the mother but also for her emotional wellbeing. Parents told us that having to retell their experience repeatedly caused them unnecessary distress and they felt that effective communication across teams could have prevented this. Some charities provide women with stickers to use on their

hospital notes to alert healthcare professionals of a previous loss and this approach is now being used on electronic patient records. We recommend that an NHS-wide flag system should be implemented, so that pre-24-week baby loss can be highlighted on parent's patient notes. This will help healthcare professionals to be aware of any previous losses and assist them in providing a compassionate and sensitive care experience, without the individual having to repeatedly recount their story of loss.

- 137. Service providers should work together across an ICS or other geographic network. This approach should also facilitate multi-disciplinary, multi-professional teams to provide excellent aftercare support to women and their partners. The benefits of working across such networks could include:
  - A local pathway from hospital care to discharge to ensure that the GP, Community midwife, Health Visitor and other key professionals are notified and aware of the loss through, for example, a detailed discharge summary from hospital or a phone call.
  - A regional system to cancel all subsequent scan and antenatal appointments so that letters/text message reminders are not sent.
  - A regional co-developed template that can be adapted for each type of loss for use by hospital or primary care services has been included in Annex G, so that a personalised letter may be sent to parents acknowledging their loss. This could also provide information on relevant national and local support that is available.
  - A consistent approach to providing pre-discharge written information about what to expect physically and emotionally with details of who they should contact if they have any concerns or complications.
  - Clear signposting to appropriate local and national support and counselling services with leaflets and support materials available or accessible in a variety of languages and formats.
  - Assurance of the use of a NHS universal flag system for paper and digital notes, so any care giver can immediately see that the patient has previously had a loss.

#### **Mental Health**

- 138. Research studies have shown that some women experience high levels of PTSD, anxiety, and depression following early pregnancy loss and that these conditions remain at clinically important levels for many months after the loss <sup>77,78,79,72</sup>. A 2019 large, multi-centre cohort study in three London hospitals found that:
  - 29% of women met the criteria for PTSD one month after an early pregnancy loss<sup>80,81</sup>.
  - This decreased to 18% nine months after the loss (miscarriage = 16%, ectopic pregnancy = 21%).

- Moderate/severe anxiety was diagnosed in 24% of women one month following a loss, decreasing to 17% after nine months (miscarriage = 17%, ectopic pregnancy = 23%).
- Moderate/severe depression was diagnosed in 11% of women following a loss, decreasing to 6% after nine months (miscarriage = 5%, ectopic pregnancy = 11%.
- 139. According to NICE, 'grief following miscarriage is comparable in nature, intensity, and duration to grief reactions in people suffering other types of major loss'82. These figures back up a survey conducted by the Mariposa Trust<sup>83</sup> (Saying Goodbye). The survey which was conducted with people who had not only experienced an 'early term' loss (pre-12-week's gestation), but also people that had experienced a late term miscarriage (up to 24-week's gestation), stillbirths, neonatal and early years loss, saw:
  - 41% of women reporting they suffered PTSD for a time following baby loss.
  - 36% of women reporting they still were suffering with PTSD following baby loss.
  - 50% of women reporting they suffered clinical depression following baby loss.
- 140. Other factors in the mother's life that may contribute to the development of PTSD, anxiety and depression following baby loss include things like the loss being a planned or not planned pregnancy, a history of infertility or long periods of trying to conceive, no warning signs of the loss, prior miscarriages or loss at a later gestational age, physical health and/or mental health issues, not having any living children, social isolation, relationship problems between partners, younger maternal age, and lower socioeconomic status<sup>66,71,84,85</sup>.
- 141. In 2019, the Baby Loss Awareness Alliance report, 'Out of Sight, Out of Mind Bereaved parents falling through the gaps in mental health care'<sup>86</sup> found that 60% of parents following baby loss felt that they needed specialist psychological support for their mental health but were not able to access it on the NHS. This was reflected by the healthcare professionals we spoke to. They highlighted the importance of providing perinatal mental health support, particularly given that in many cases specialist perinatal mental health teams do not currently accept referrals for mothers who experience baby loss pre-24 weeks gestation.
- 142. It is important that the support offered to parents is appropriate to their situation. Emotional support after the loss, either through counselling or referral to peer-support groups is important, as well as follow-up from the health care provider<sup>87</sup> and referral to specialist care if necessary. Some parents told us that the support they were offered was not always appropriate; some had been offered group therapy which was intended for individuals suffering from depression. One father revealed that he had been offered an anger management course and felt that this was very unhelpful and exacerbated his emotional distress. In other cases, women and their partners will need more intensive

- specialist evidence-based psychological therapy and this should be available to them should it be required.
- 143. NICE guidelines on antenatal and postnatal mental health include guidance on caring for women who have experienced miscarriage<sup>88</sup>, however there is no best practice guidance around how healthcare professionals identify the mental health needs of women and their partners following a baby loss. More generally, parent-support groups that we spoke to emphasised the need to improve awareness amongst NHS staff about the psychological impact of the loss and the increased risk of suicide following pregnancy loss.<sup>70,89</sup> A survey conducted by the Mariposa Trust (Saying Goodbye) of 338 people, saw 49.41% of responders report that they had considered suicide after baby loss with 7.35% attempting to end their own life<sup>90</sup>. 16.47% also reported that their partner had suffered suicidal thoughts following their baby loss.

#### **Partners**

- 144. Partners also display depression and anxiety.<sup>72,91</sup> While there is mental health screening and resources allocated for antenatal and postnatal mental health of women, there is a need to address the gap in perinatal mental health provision directly after a baby loss to ensure that partners are able to access appropriate psychological support. According to the survey of Bereavement Midwives<sup>92</sup>, although emotional support is commonly offered to women, 46% of respondents reported that it is not routinely offered to partners or spouses.
- 145. The feelings associated with baby loss are very similar for both men and women, but men often feel the need to take on the 'supporter' role, potentially at the expense of their own mental wellbeing<sup>93</sup>. There is a lack of social recognition of the loss, often leading to 'disenfranchised grief' for men as well as challenges in accessing support. Both parents should be treated equally when it comes to the provision of aftercare and emotional support. In many cases, the parents we spoke to said that only the mother was offered emotional support, when the father/partner had been equally distressed by the loss and very much needed support and/or counselling. Adequate mental health support should be available to all parents, including partners, experiencing pre-24-week baby loss. This support should be available in a wide range of forms, including one-to-one psychological care, group sessions, religious/spiritual care and support, all taking place in appropriate and sensitively considered settings.

## Developments in Mental Health Support for baby loss

146. The NHS Long Term Plan<sup>94</sup> aims to increase access so at least 66,000 women can access specialist perinatal mental health services by 2023/24. Maternal Mental Health Hubs are expected to be available across the country, combining maternity, reproductive health and psychological therapy for women experiencing mental health difficulties directly arising from, or related to, the maternity experience including early pregnancy loss. In addition to the expansion of specialist community perinatal mental health services, 33 maternal mental health services are being established for women who experience moderate to severe or complex mental health issues directly related to a trauma or loss. NHS England's ambition is to have one in each ICS by 2024. We look forward to

seeing if this model will be successful and we hope all hubs will be easily accessible to all women.

- 147. In June 2022, the NIHR Public Health Research (PHR) Programme published its intention to commission research into which population-level interventions are the most impactful in improving mental health outcomes in women or/and partners experiencing a pregnancy not ending in a live birth in the UK (includes miscarriage, ectopic pregnancy, medically indicated and choice termination, stillbirth and neonatal deaths). Programme published its interested in are extensive and include:
  - Evaluations of interventions to support parents from a diverse range of cultural and socio-economic backgrounds and LGBTQ+ individuals who have experienced pregnancy not ending in live births including interventions delivered by charities
  - How workplace policy and interventions can support parents experiencing pregnancy loss
  - The effectiveness of different types of psychosocial interventions on different types of pregnancy loss
  - Why some women and/or partners who have experienced pregnancy not ending in live birth do not access support, either through lack of awareness of services, the nature of the services themselves or because of personal preference. Likewise, what are the consequences of the lack of engagement with services.
  - How bereavement interventions for other types of loss can be adjusted and used to support parents experiencing pregnancy loss
- 148. Effective communication is crucial between healthcare professionals regarding parents who may be at risk of developing or who have been diagnosed as having mental health problems following baby loss.
- 149. A mental health check-up should be available to all women and their partners following pre-24-week baby loss and either a clinical referral made or a self-referral encouraged. Any woman or her partner with deteriorating mental health or who is displaying risk factors for suicide or self-harm should be prioritised for immediate assessment.
- 150. Sufficient time must be available in follow-up appointments with bereaved parents to enquire about their emotional well-being and to offer information on self-referral support or other forms of psychological therapies should it be required.

## **Subsequent pregnancies**

151. It is never possible to predict how individual parents will feel during subsequent pregnancies and therefore it is essential that all NHS staff offer parents sensitive care throughout their subsequent pregnancies. Parents should feel well supported in any pregnancy, especially following a previous loss. All

staff in primary and secondary care settings seeing bereaved parents before, during and after a pregnancy following a loss must be aware of and acknowledge the potential difficulties and challenges these parents might face. It is important that healthcare professionals listen to and acknowledge parents' fears and concerns and outline any additional antenatal care and psychological support that is available to them. A robust documented management plan should be in place for all future pregnancies and should be agreed with the woman and where appropriate, her partner. Healthcare professionals should offer support information and books for parents to utilise during subsequent pregnancies to help them manage fear and anxiety.

## Support

- 152. For many people who have experienced baby loss, discovering that they are pregnant again can bring with it a mixture of hope and fear, along with a range of other emotions. Women who get pregnant less than a year after a miscarriage are at higher risk of psychiatric symptoms. They are also at more risk of pregnancy related distress about the birth, their relationships or their emotions<sup>96</sup>.
- 153. Pregnancy after loss clinics should be established at each hospital offering maternity care. When a family is expecting a baby following loss, additional clinical and psychological support is often required. By offering specialist support, individuals feel heard and understood. Existing clinics also report a reduction in subsequent loss when additional specialist support is provided. We visited Professor Alex Heazell at St Mary's Hospital in Manchester and were extremely impressed at the 'Rainbow Clinic' he leads.

## Recurrent pregnancy loss

- 154. If a woman has experienced more than one pregnancy loss, health care professionals should ensure that additional antenatal and emotional support is provided and a clear management plan is communicated to the woman and where appropriate to her partner or other family member. We believe that specialist recurrent loss clinics should be established in each Integrated Care Region where specialist provision for women who have experienced recurrent loss is available, and swift referral should be encouraged.
- 155. Working with the relevant Royal Colleges, NHS England should develop standardised primary and secondary care clinical standards for pre-24-week baby loss that local service providers and commissioners can use to update their local guidelines and service provision.
  - If individuals experience a pre-24-week baby loss, and request an
    appointment with their GP practice, a person-centred consultation should
    be offered to them. If appropriate or requested, the individuals' baby loss
    experience and future pregnancies should be discussed during this
    appointment. Support information about the emotional impact and potential
    trauma following baby loss should be provided, and individuals should be
    advised that they can self-refer to NHS Talking Therapies. Clinicians
    should actively encourage this self-referral if they feel it would benefit the
    individual.

- Following two losses, an appointment should be made for blood tests, including full blood count and thyroid function and other necessary investigations. Depending on the results of these tests, along with any other pre-existing or chronic physical or mental health conditions, referrals should be made to the relevant specialism.
- A consultant-led appointment should be offered following three losses, at a specialist recurrent miscarriage centre where possible, so additional tests, including genetic testing, scanning, screening and treatment, can be offered.
- The standardised primary and secondary care clinical guidelines should include flexibility to give priority to accommodate differing factors such as advanced maternal age, infertility, recurrent loss, and other medical conditions.
- 156. Analysis of data from the PRISM (Progesterone in Spontaneous Miscarriage) trial a multicentre, double-blind, placebo-controlled randomised trial of progesterone in women with early pregnancy vaginal bleeding found that although progesterone treatment did not reduce the rate of miscarriage for those with no previous miscarriages, there was a small reduction in miscarriage for those with one or two previous miscarriages and a large reduction in miscarriage for those with three or more previous miscarriages<sup>97, 98</sup>. Based on this research, NICE updated its guidance, 'Ectopic pregnancy and miscarriage: diagnosis and initial management'<sup>99</sup> in 2021 recommending treatment with vaginal micronised progesterone, 400 mg twice daily, for patients with an intrauterine pregnancy confirmed by a scan, if they have vaginal bleeding and have previously had a miscarriage. If a fetal heartbeat is confirmed, this progesterone treatment should be continued until 16 completed weeks of pregnancy. Doctors should routinely prescribe this treatment for patients who meet the NICE criteria, however, despite this guidance, patients are still fighting to receive it.
- 157. Individuals recognised as high-risk for baby loss at booking or any time during pregnancy should receive personalised care pathways, which may include a higher level of care and monitoring.
- 158. If a home pregnancy test shows a positive pregnancy result 3-weeks following a baby loss or pregnancy symptoms persist, further medical management should be offered to the individual. This may include clinical review, repeated urine tests, blood tests to check for pregnancy hormones and/or an ultrasound scan. This is to ensure that no pregnancy tissue has been retained and to avoid infection and other complications. Investigations such as routine post loss blood tests, scans, infection screening, post-mortem examination and placental histology should be offered to all women experiencing mid-trimester loss. Where an ectopic or molar pregnancy is suspected or has been confirmed, the individual and their partner should be given information about signs of infection, who to contact and what to do if pain and/or bleeding persists or becomes heavier and details about their management and any follow-up appointments. They should also be given the details of support organisations (see Annex H) and offered additional resources to help them emotionally.

- 159. Clear integrated care pathways must be established across primary, community and secondary care. This must also include the updating of IT systems, which can communicate with GP's IT systems to ensure that GPs, community midwives, and health visitors are notified of a loss promptly.
- 160. In a subsequent pregnancy, an early reassurance scan should be offered and the woman and her partner should be signposted via their midwife to appropriate services such as ongoing emotional support and psychological support where indicated to help manage anxiety levels. In addition, information and resources should be offered.

# Chapter 7. Supporting and empowering staff

- 161. NHS staff play a critical role in ensuring that parents experiencing pre-24-week baby loss receive high quality care and support, are signposted to appropriate services and understand the options available. Many parents spoke about the sensitivity and kindness that staff caring for them demonstrated.
- Employees from across the complete employment spectrum experience vast 162. differences in the level of support and empathy offered to them by their employers. We acknowledge and commend the organisations that have made significant strides in developing new policies and practices to support their employees who experience baby loss. Whilst it is not possible for us to force change in employment law, we would like to see all businesses adopting a more proactive approach and the introduction of policies to safeguard and support staff experiencing a pre-24-week baby loss. We would encourage employers to utilise existing information and resources that are available to support this work. Funding such as the Voluntary, Community and Social Enterprise (VCSE) Health and Wellbeing Fund has enabled a significant amount of training to already take place, and we hope that this will be continued beyond 2025. Third sector organisations such as the Miscarriage Association, The Mariposa Trust (Saying Goodbye), Sands, Abigail's Footsteps and others have pioneered training and resources in this area. The Miscarriage Association have developed a 'Pregnancy Loss Pledge' which can be adopted by employers. Furthermore, the Mariposa Trust (Saying Goodbye) have the 'Mariposa Gold Standard Award' which is given to companies who have undertaken bereavement training and have implemented people-centred baby loss policies.
- 163. Whilst there is a clear acknowledgement that staff working in hospitals and community settings are often under intense pressure with limited time to interact with parents, demonstrating compassion and sensitivity is extremely important. Bereavement training and education is fundamental in nurturing these vital communication skills, however it was noted that a lack of resources and funding often make it difficult for staff to access training opportunities. Regular updated bereavement training is essential in order for all staff working with loss, including those working in primary care to be able to offer high quality consistent care and support.

# **Staffing**

- 164. Our visits to EPAUs highlighted the difficulties they face recruiting and retaining high quality doctors, nurses, sonographers and administrative staff. This is primarily due to the relentless demands on services and the nature of the care that staff provide resulting in compassion fatigue, stress and burnout.
- 165. Some EPAUs care for 1,000 or more women every month. EPAU staff told us that one of the big issues is they are only given 15 -20 mins per patient to perform a scan, take blood tests, provide good or bad news, and advise on any next steps regarding their care. Staff feel that they are not given enough time to provide high quality, compassionate care. One explanation we were given for the short appointment times is that reassurance scans, arguably the bulk of work in many EPAUs, were paid for under the Maternity Pathway Payment System's

Antenatal Pathway Tariff. Under this system, a cross charge should have been made between the maternity and gynaecology departments for reassurance scans. It was common for such cross charges not to be made, and in some Trusts, this could have contributed to the gynaecology department operating at a deficit. This approach to paying for services changed in 2020. In theory, all departments should now be paid for the services they provide.

166. We witnessed large variations in the numbers of staff working in early pregnancy services, including their competencies, training, and the skill mix of the teams. EPAUs may be consultant-led or nurse-led. We are not able to know the numbers of doctors, nurses or sonographers working in early pregnancy care — this information is neither collected nor published.

## Specialist Training

- 167. Currently, although specialist training programmes are available for both doctors and nurses, there are no requirements for clinicians working in or managing EPAUs to have any training qualifications specifically in early pregnancy loss care.
- 168. Early pregnancy care is not a sub-speciality in the RCOG curriculum. Trainee doctors who wish to pursue a consultant post in this area can undertake an Advanced Training Skills Module (ASTM) in Acute Gynaecology and Early Pregnancy (AGEP). The required competencies are developed and assessed mainly through on-the-job training.
- 169. The RCN published updated guidance on the key skills and knowledge required to develop the role of a specialist nurse/midwife in early pregnancy care in 2021<sup>100</sup>. The RCN's Women's Health Forum also carried out an impact assessment of the standards effectiveness and found wide disparities in their adoption by service providers and commissioners<sup>101</sup>. The Forum, in collaboration with the Association of Early Pregnancy Units, is currently working on ways to develop the Clinical Nurse Specialist role in this field.
- 170. We reviewed the job descriptions and person specifications for roles such as Senior Gynaecology Nurses and EPAU Advanced Nurse Practitioners. We found that in some cases specialist qualifications in gynaecology or women's health were considered to be 'desirable' rather than 'essential'. A key function of an EPAU is to provide ultrasound scans to diagnose problems in early pregnancy and a qualification in ultrasonography was required in most of the job descriptions we reviewed.
- 171. Standardised specialist training programmes in early pregnancy care should be introduced for both doctors and nurses working in EPAUs as soon as possible, to promote excellence in the system, and to provide more formal recognition of the importance of EPAUs. Trusts must provide protected time within working hours for this training.

## Bereavement training

172. Bereavement training and education is fundamental in developing the vital skills that health care professionals require to be able to offer high quality consistent bereavement care and support. However, it was noted that a lack of

funding often made it difficult for staff to access training opportunities, which needs to be addressed. Our research showed that there are many excellent examples of fully funded resources and training available, which should be better publicised in order that they may be utilised across all primary, community and secondary care, as well as to society in general.

- 173. Training and education in bereavement care and support, should be a core requirement for all staff who care for parents experiencing loss. Based on our expertise and the consultation meetings we held with parents, baby loss support charities and healthcare professionals, one of the main concerns is the lack of standardisation in bereavement care training and staff compliance with guidelines in the care pathway. Many staff do not receive adequate training to enable them to care sensitively for women who have experienced a baby loss, or to provide emotional support for partners and families. This is particularly the case for GPs, staff in gynaecology, Paramedics and A&E staff who are often the initial contact for many women. The NBCP currently provides two e-learning modules that help to guide healthcare professionals when communicating with bereaved families. Other third sector providers including Bereavement Training International, The Mariposa Trust (Saying Goodbye), Miscarriage Association, Abigail's Footsteps, Petals, Child Bereavement UK, and the Lullaby Trust also provide or fund inhouse training for healthcare professionals. Other resources including experiential videos involving people with lived experience of baby loss should be utilised to allow healthcare professionals to gain an understanding of the physical, emotional and psychological impact of loss.
- 174. Improving staff training and education in bereavement care was highlighted as a priority for the NHS following the Independent Maternity Review and the Ockenden Review<sup>102</sup>. We heard from clinicians how in some cases there are very few, if any, staff on duty who have had specific training in bereavement care and support. Bereavement care in medical training, particularly relating to miscarriage and pre-24-week loss is commonly seen as lacking and skills and competence are largely dependent on the individual healthcare professional's experience. A number of e-learning and in-person training options around bereavement care for early baby loss already exist which Trusts can enrol in. These are available from the Royal College of Midwives and various baby loss support charities. There are, however, issues around consistency and the staff members that are choosing or chosen to participate.
- 175. A recent survey published by Sands found that most midwives across 117 UK health Trusts and Boards are expected to undertake bereavement care training in their own time. Only 49% of Trusts and Boards surveyed provided bereavement care training to staff and only 12% of those who did allow for that training to happen during working hours. The survey also found that:
  - 48% of midwives, 33% of student midwives and 27% of obstetricians and gynaecologists and 39% of ultrasound practitioners are offered annual bereavement care training by their Trust or Health Board; and
  - Most training is only for 60 minutes. Only 6% of midwives and 1% of obstetricians and gynaecologists receive one-half or one whole day of training.

- 176. Training and education for all staff within the care pathway needs to be multidisciplinary and mandatory, seen as a core part of continuing professional development and funded and recognised/rewarded accordingly. If possible to include techniques such as simulation and service user input. In addition to ensuring that staff receive the appropriate level of training, there is a clear need to ensure awareness and compliance to relevant clinical and bereavement care guidelines.
- 177. In addition to the importance of training in providing better care and support to parents who have had a baby loss, training is also an important element for the wellbeing and confidence of healthcare professionals. Recent research suggests that doctors who receive breaking bad news training report higher levels of confidence and sonographers who have received post-qualification new delivery training report lower burnout<sup>104</sup>.

# Staff support and self-care

- 178. Recognising the emotional impact on staff caring for women during a baby loss is crucial to safeguarding their well-being as individuals and more broadly, ensuring retention of the workforce. We heard from Bereavement Midwives how compassion fatigue is a huge issue with professionals working with loss across England. Those we spoke to felt a lack of education exists regarding the importance of good bereavement care, particularly amongst managers, some of whom consider it to be merely 'tea & sympathy'. Many professionals expressed feeling undermined and angry that they were being undervalued and unappreciated.
- 179. A significant number of NHS staff will personally experience baby loss. The impact of their loss should not be underestimated, and a sensitive and flexible approach should be taken when they return to work. The NHS Confidentiality Policy that all NHS staff must observe, restricts the personal information that NHS staff are able to share publicly. One of the unintended consequences of this, is that this limits NHS staff accessing the baby loss support that is available via social media platforms and public support groups. It is essential therefore, that comprehensive support is offered by the NHS to all healthcare professionals who experience a loss, to ensure that their mental and emotional health needs are adequately met.
- 180. The COVID-19 pandemic has put maternity services under unprecedented pressure. Changes to care pathways, the closure of some units, understaffing due to sickness absences and restrictions on partners being able to attend appointments and scans all put extra burdens on maternity staff and ultrasonographers with serious implications for their health and well-being. Many specialist Bereavement Midwives were pulled from their roles due to staff shortages.
- 181. In the most recent NHS staff survey for 2022<sup>105</sup>:
  - 39.7% of nurses and midwives said they felt burnt out because of their work, second only to operational ambulance staff.

- 50.3% of nurses and midwives felt unwell as a result of work-related stress.
- 52.5% of all staff said they achieve a good balance between work life and their home life.
- 182. Studies carried out on the impact of baby loss on midwives tend to focus on stillbirths. One study on the perceptions of midwives caring for women experiencing early baby loss found that repeated exposure to early pregnancy loss can have a profound emotional effect on midwives, with a potential for this to affect the care that women receive. Midwives identified the need for further education in the area of early pregnancy loss, time out during the shift to debrief, and counselling for staff. The authors concluded that structured support is needed for midwives and other health professionals where there is repeated exposure to early pregnancy loss.
- 183. Reflective supervision in particular was seen as an essential way of supporting staff in the care pathway. Staff debriefs and peer support were also highlighted as important ways to help support staff and avoid compassion fatigue and burnout.

### **Bereavement Teams**

- 184. Specialist staff trained in bereavement care, such as Bereavement Support Specialist Midwives have a vital role in the baby loss care pathway. There is no consistent grade level and each hospital dictates how many hours they are willing to assign to bereavement work, which varies greatly and often depends on budget.
- 185. Bereavement midwives revealed concern over the lack of workforce and hours provided to deliver the full gamut of support required. We were told that this was often because of a lack of understanding and therefore support from management of the role, resulting in many bereavement midwives shouldering a disproportionate amount of responsibility themselves. They also spoke about how many burn out quickly due to the sheer volume of the work and the psychological impact on them working with loss on a daily basis. There is also no standardised training for bereavement midwives or guidance around the level of care or intervention that is expected of the role.
- 186. Some bereavement midwives practice clinically, as well as offering bereavement support, whilst others purely offer a support-based service. Several bereavement midwives we spoke to disclosed that their hours were the first to be cut by Trusts in times of financial hardship and that they were regularly pulled from their bereavement role to work clinically when there were staffing shortages.
- 187. The discrepancy in role, hours and pay was felt to be a real issue and that it showed there is little regard for the role. We heard that many bereavement midwives feel it necessary to work many additional hours work in their own time. According to the bereavement midwife forum, compassion fatigue is a huge issue with bereavement midwives across England.

188. Another contributory factor to stress and burnout may be that only a small minority of bereavement midwives receive counselling supervision or any kind of emotional support on a regular basis, and this needs to be addressed.

# Chapter 8. Certification scheme for pre-24-week baby loss

- 189. When the review was commissioned, the terms of reference asked us to consider the impact on families of the current threshold of 24 weeks before being able, formally, to register a baby loss if they so wish, and also whether it would, on balance, be beneficial to look at legislative options to amend existing primary legislation to allow parents to register a baby loss if they so wish.
- 190. Currently, parents whose babies are born without signs of life after the 24<sup>th</sup> week of pregnancy must register the birth as a stillbirth. The parents will receive a certificate of registration of stillbirth. When a pregnancy ends before the 24<sup>th</sup> week of gestation, the loss is considered to be a miscarriage. There is no formal process for parents to legally register this type of loss, as current legislation excludes pre-24-week gestation loss, leaving parents without the formal recognition that many of them long to have. Instead, hospitals may enter a baby's name in a local book of remembrance or issue a local certificate to commemorate the loss for those parents who wish to do so. The Mariposa Trust (Saying Goodbye) have been campaigning for the introduction of a certificate of life since 2015.
- 191. Feedback from consultation meetings conducted as part of this review with parents, baby loss and bereavement charities and healthcare professionals suggest that a strong case can be made for setting up a certification scheme to give official recognition for pre-24-week gestation baby loss. Many parents who have experienced a baby loss feel that having official recognition of their loss, in the form of a certificate from the government, would help in the grieving process. We are aware, however, that the experience of baby loss is highly individualised. Some parents will see the value in an official government issued 'Baby Loss Certificate' scheme, while others may feel distressed if this were made mandatory.
- 192. Online surveys conducted by Sands, The Mariposa Trust (Saying Goodbye), and the Miscarriage Association show that a significant majority of respondents are in favour of some form of official recognition for pre-24-week baby loss. Moreover, more general feedback from charities suggest that many parents would like their loss recorded.

# **Current process for registering stillbirths in England and Wales**

- 193. When a baby is stillborn, the stillbirth must be recorded in the stillbirth register. The process for registering a stillbirth, typically at a local authority registry office, combines features of both birth and death registration.
- 194. Stillbirths as with marriages, civil partnerships, deaths and births are entered into an official register by a registrar and the records are sent to the General Register Office (GRO). The data is also used by the Office of National Statistics (ONS) to produce national statistics.
- 195. The current procedure for registering a stillbirth in England and Wales is set out in Figure 11. A stillbirth should be registered at a register office within 42 days<sup>107</sup> <sup>108</sup>. The name of the baby can be included in the register. Stillbirths must

be registered in the district in which it takes place. Those who cannot get to the district where the stillbirth took place can speak to another registrar who will record the details on a form of declaration and send it to the registrar for the district where the stillbirth took place. Either parent can register a stillbirth (or they can do this together) if they are married or in a civil partnership. If the parents are not married or in a civil partnership, the mother or father can register the stillbirth if they have a signed declaration from the other parent (or they can do this together). If neither parent can attend, the following people can register the stillbirth: the occupier of the hospital or house where the stillbirth took place, someone who was present at the stillbirth, someone who is responsible for the stillborn child, or person who found the stillborn child, if the date and place of the stillbirth are unknown.

196. The person registering the stillbirth needs to take the medical certificate of stillbirth that the doctor or midwife attending the stillbirth is required to issue.

## Figure 11: Current procedures for registering stillbirths in England and Wales

- 1. The doctor or midwife who was present at the birth or examined the body will issue a medical certificate of stillbirth.
- 2. The person who registers the stillbirth takes this certificate to the local register office. It is free to register a stillbirth, and the appointment takes about 30 minutes.
- 3. The Registrar enters the information on the Registration Online (RON) system hosted by the General Register Office (GRO).
- 4. The Registrar prints out a register entry, which the person registering the stillbirth checks and signs. This is the legal record.

# For parent s/ family

- A short certificate that the registrar has registered the stillbirth can be given to the parents at the time of declaration free of charge.
- The registrar will also issue
  a certificate for the burial or
  cremation of the stillborn
  child on an official burial or
  cremation site. The
  certificate is normally
  passed to the funeral
  director who is making the
  arrangements. A funeral
  cannot take place until this
  certificate has been given
  to the burial authority or the
  crematorium.
- 3. A certified copy of the register entry showing the parents details can be purchased for a fee and ordered at the time of declaration or another time in the future.

#### Obtaining certificate for an historic stillbirth entry

Due to the sensitive nature of stillbirth registrations, the procedure for ordering a copy of a stillbirth entry differs from other types of certificates. Apart from very recent events, the General Register Office holds records of all stillbirths registered in England and Wales since 1 July 1927. Certified copies of these records can only be obtained with the Registrar General's consent. The following conditions apply: a certificate will only be issued to the mother or father of a stillborn child; siblings may apply if their parents are deceased - details of their parents' dates of death should be sent with the application; stillbirth certificates can only be obtained from the General Register Office in Southport.

# For the national record

- The Registrar makes and delivers quarterly to the Superintendent Registrar a true, certified copy of all the entries of stillbirths kept in the local register.
- The Superintendent Registrar verifies and if found to be true, certifies the copy of all the entries of stillbirths kept in the local register. Quarterly, the superintendent registrar sends all certified copies of entries of in registers of stillbirths to the Registrar General.
- When a register of stillbirths is filled, the Registrar shall deliver it to the Superintendent Registrar, who shall forward it to the Register General.
- 4. The registrar also sends 'compulsory' and 'voluntary' statistics about the stillbirth to the Office for National Statistics.

# Certificates of recognition of early baby loss - International practice

- 197. Certificates of recognition of early baby loss<sup>a</sup> are currently administered in several states in Australia, in the United States of America and Germany.
- 198. In Australia, the Northern Territory Registrar was the first state to begin issuing an 'Early pregnancy loss recognition certificate' in 2007, and was subsequently followed by South Australia, Queensland, New South Wales, Tasmania and Western Australia. These certificates are issued on a non-statutory basis by state registrars and are free of charge to applicants. A closed register is maintained by state registrar offices for the purpose of issuing duplicate certificates (rather than to produce data for health research or other public records). Medical verification is required to make an application.
- 199. Florida began issuing 'Certificates of non-viable births' in 2017. HB 101, the Grieving Families Act, gives parents the option of receiving a state-issued certificate if a pregnancy loss occurs between nine weeks and twenty weeks of gestation. The scheme requires medical verification and applicants are charged a nominal fee. A closed register is maintained by the Office of Vital Statistics at the Florida Department of Health. Other American states issue 'Certificates of Fetal Death'.
- 200. We spoke to government officials in New South Wales Australia and Florida USA to understand how their schemes have worked in practice. In both cases, officials stated that the process of setting up the scheme was relatively straightforward and low-cost.

# Designing a certification scheme for England

- 201. In exploring options for a pre-24-week baby loss certification scheme, we consulted parents, charities, UK government officials and registrars to understand the demand for a scheme, the challenges involved in setting up a scheme, how it could be administered and by whom. Key points that were raised in feedback on these questions included:
  - Voluntary: While many parents and bereavement charities support the
    idea of setting up a certification scheme for pre-24-week baby loss,
    following an extensive consultation process, it was felt that a voluntary
    scheme was needed, to ensure parents who would prefer not to have a
    certificate are not forced to do so. Offering parents, the option of whether
    or not to obtain a certificate of loss constitutes a significant difference from
    the current registration process for stillbirths, which is a statutory
    requirement as set out in the Births and Deaths Registration Act of 1953.
  - Parent-centred: Parents and charities with whom we spoke, agreed that
    the primary purpose behind setting up a scheme of recognition of pre-24week baby loss is to help parents with the grieving process. While some
    recognised the value in using the data that might be generated from the
    registration of pre-24-week baby loss, especially in light of the lack of
    robust statistics in this area, it was felt that this should not be a priority.

<sup>&</sup>lt;sup>a</sup> Legal definitions of stillbirths vary between countries. The term 'early baby loss' here is used to designate baby loss that is not stillbirth.

Furthermore, it was not clear whether there would be value in this, given the voluntary nature of the scheme.

- Inclusive: Parents and charities who provided feedback overwhelmingly felt that any scheme recognising pre-24-week baby loss should be as inclusive as possible. As such, it was felt that the certificates should be open to parents who had losses at any gestation, include retrospective losses and to make medical verification of the loss optional (depending on the preference of the applicant). Further to this, given the importance of terminology and the recognition of the wide variation in how parents choose to speak of their loss (some preferring to use 'baby' while others may prefer to use the term "the pregnancy loss"), parents could be given a limited set of options for the language used on the certificate. In keeping with this, many charities and parents felt that medical verification should be made optional, as whilst it was felt that this provided greater legitimacy to the certificate, parents where medical verification was not possible (for example, early losses or losses that had taken place outside of the healthcare system, i.e. at home) would not be excluded.
- Official: Charities, as well as parents, felt that the certificate would need to be issued from a government body, otherwise it would not be offering the 'official' recognition that many parents need. It was felt that, whilst the commemorative certificates that are offered by charities and hospitals are appreciated by some, bereaved parents above all wanted official recognition from a government-issued body.
- Free of charge: If possible, there was a consensus that certification should be made free of charge. Many advisory panel members recognised that this might be difficult and were open to considering options where parents might be charged a fee (which would ideally be a nominal amount), although provisions would need to be made for disadvantaged groups without the means to pay.
- Accessible: Information about certification should be available within, if not directly available from, all healthcare settings where people experiencing baby loss may access care, including all primary and secondary care facilities.

# **Certification or Registration**

- 202. The Registrar General for England and Wales (RG) is a crown appointment and the role and duties are very specific and laid out in law. The RG's office, The General Register Office (GRO) currently manage registers which are all defined in legislation. Details of births, deaths, still births and marriages are captured on behalf of the RG by registrars who are local authority employees. There are strong links around data collection and purpose with information fed to the ONS for publication purposes.
- 203. Therefore, as precedent currently stands, a register of pre-24-week baby loss would have to be defined in legislation and would therefore require the scheme to be mandated and not optional. It would also consequently likely require some

form of evidence that the event has taken place. Due to the considerations set out previously, we feel that a registration process would not be appropriate for pre-24-week baby loss and have chosen therefore to recommend a baby loss certification scheme instead.

# **Summary – Certificate of Baby Loss:**

The Government should introduce a voluntary scheme to enable parents who have experienced a pre-24-week baby loss to receive an official certificate to provide recognition of their loss. The purpose of issuing a certificate is to provide comfort, to help parents validate their loss and to show that the government acknowledges that a life has been lost. The scheme should have the following features:

**Voluntary**: Women and their partners who have experienced a pre-24-week baby loss should have a choice, rather than be required, to apply for a certificate.

**Medical verification optional:** Parents applying for a certificate can opt to include medical proof from a healthcare professional to officially confirm their baby loss took place.

**Any gestation:** Parents will be able to apply to receive a certificate for baby loss at any gestation pre-24-weeks.

**Retrospective:** Parents who have experienced a historic baby loss (i.e., occurring before the launch of the scheme) will also be able to obtain an official certificate.

**Official:** The certificate should be issued by the government.

**Digital:** Parents should be able to have the option to apply online and download the certificate themselves, For the digitally excluded, an alternative option should be made available.

**Closed register:** Records of all applications for certificates will be kept in a central database, which will not be searchable or accessible to the public.

**Non-legal document:** The certificate will not be considered a legal document. Parents receiving a certificate will not currently be entitled to further benefits by law.

**Identification Verification:** This will be required for any application.

# **Chapter 9. Conclusion**

We took on the role as co-chairs of this Review in the hope that we could transform the landscape for pre-24-week baby loss care for this generation and for future generations, and it feels surreal to be now writing the final pages of this report. We were initially given 6-months to examine the crisis in pre-24-week baby loss care, however due to the sheer magnitude of the issues we were tasked with reviewing the 6 months' timescale was not realistic. Little did we know that the review would take five years to complete, and whilst Brexit and the Covid-19 pandemic paused the work for some time, we still feel that we have only just scraped the surface of the mountain we have had to climb in carrying out this huge body of work.

Though the journey has been a long and arduous one, it has been a great privilege and an honour to have witnessed many excellent examples of care within the primary and secondary care settings that we visited. Conversely, we were saddened and appalled to hear about and observe some truly shocking practices which require immediate intervention.

An estimated 254,000 babies die in pregnancy or at birth each year in the UK; This means that since this review commenced, approximately 1,270.000 babies have died, leaving millions of parents, siblings and extended family members heartbroken. Whilst it is not possible to prevent many of these losses from occurring, we can ensure that each grieving parent receives excellent care and compassionate support, and we all have a responsibility to do this.

Our hope and trust are that the recommendations we have made in this report are swiftly and effectively implemented. Some recommendations will offer an immediate difference, while others will take many years to alter practice. Nonetheless, it is vitally important that this transformation starts as quickly as possible.

As leaders working in the field of baby loss, but just as importantly as mothers who, ourselves, have experienced baby loss, we hope that this review is a catalyst for lasting change.

And to every family who has had to say goodbye to a much-loved baby

...We dedicate this work to you.

# Annex A. Detailed recommendations

- 1. Implementing these recommendations is imperative to improving future care and support for individuals and their partners experiencing pre-24-week baby loss. Therefore, we recommend establishing a 'Pregnancy Loss Review' working party, chaired by us, which will ensure that the recommendations and best practice points within this report are actioned.
- om the work of the review and our professional experience. These problems do not necessarily exist in every primary and secondary setting, and they are certainly not representative of every healthcare professional. Healthcare professionals working with loss are under huge stress and work under ver he highlighted problems and impacts are based on evidence gained from the broad spectrum of meetings, consultations and patient/parent feedbac ifficult circumstances and it's important that we acknowledge this, whilst simultaneously addressing elements of care that need to change. ĸi

Review Recommendation	1. The Department of Education must expand the current Relationship, Health and Sex Education (RSHE) guidance for schools to include education on all types of baby loss, not just miscarriage. The supporting teacher training modules should also include information on symptoms of baby loss, how to access care, and where to access support. Whilst we understand teachers do not want to distress students, it is inappropriate to say that we do not educate people in case we upset them.
Ways in which best practice could be achieved	Ensure schools have access to high-quality resources to support teaching about pre-24-week baby loss.
Best Practice	Everyone should have a basic understanding of pre-24-week baby loss before they become pregnant.  The Department for Education's 'Statutory guidance for governing bodies, proprietors, head teachers, principals, senior leadership teams and teachers on Relationships and Sex Education' states that by the end of secondary school, pupils should know the facts about pregnancy and baby loss.
What is the impact	Young people are unaware of the scale and impact of baby loss and infertility. They are unprepared for family members going through this or experiencing this themselves later in life. They are also unaware that their reproductive life span is limited and that pregnancy issues, infertility and many health conditions can impact pregnancy and fertility. This may result in physical and mental health issues.
What is the problem	A lack of primary and secondary education regarding baby loss and infertility.  The lack of education means that when people decide to have children they lack vital information. People are waiting longer to have children and are unaware that their risk of loss increases with factors such as maternal age.
Topic	Education, Training and Information (Schools)

Topic	What is the problem	What is the impact	Best Practice	Ways in which best practice could be achieved	Review Recommendation
		They are also unaware of where and when to access help if they are experiencing pregnancy or fertilityrelated issues.			
Education, Training and Information (Society)	A general lack of education and awareness regarding pre-24-week baby loss services.	Because of the lack of education, people are often unaware of the symptoms of baby loss, when emergency treatment is required, where to access the treatment they need, and where to find support.	Women and their partners should know whom to contact and should know where to go to access care at any time of the day or night if they are experiencing either pain, bleeding or both prior to 24 weeks gestation. Healthcare professionals should give this information at the point of a confirmed pregnancy or the first maternity booking appointment.  When seeking advice, the concerns of individuals should be listened to and sensitively managed. The individual should be directed to the most appropriate place of care based on their symptoms and given	Pre-conceptual care providers such as sexual and reproductive health clinics and pharmacists should use opportunities to educate individuals on fertility/infertility and loss.  GP services must ensure clear information is displayed and available for each person with a confirmed pregnancy.  Awareness needs to be raised pre-pregnancy of local pre-24-week baby loss services such as Early Pregnancy Assessment Units in places where women access care, e.g. reproductive health services and through	<ol> <li>NHS England should commission the development of a poster on 'what to do if you have pain or bleeding during pregnancy' to be made available to GP practices, sexual health clinics, pharmacies, and Women's Health Hubs.         The poster should include a QR code to link to more information and should have space for contact details for local services.     </li> <li>NHS England should work with NHS Trusts and their Maternity Voices Partnerships to review the quality and accessibility of information regarding pre-24-week baby loss, including what information should be given at the first antenatal visit, and what to do and how to access services if there is</li> </ol>

Review Recommendation	pain and bleeding in early pregnancy. This information should include a list of local services and the care they can expect to receive, as well as emergency contact numbers and medical guidance on managing symptoms. People should know what to expect in advance. This information must be available in all languages and in Easy Read and digital formats.  4. NHSE Transformation Directorate in partnership with Sam Collinge and Zoe Clark-Coates, should undertake a review of the availability and accessibility of information on 'what to do if you have pain or bleeding in pregnancy across all NHS digital platforms including www.nhs.uk, NHS Apps and Maternity Notes Apps (e.g. BadgerNotes) and take steps to ensure all information is clear and easily accessible. This
Ways in which best practice could be achieved	information including digital sources.  NHS Trusts that provide pre-24-week baby loss care already provide information (website and leaflets) about what to do and how to access their services. Still, this information varies in quality and accessibility and can be hard to find. Services should work with their Maternity Voices Partnerships and integrated care systems who commission women's health services including Women's Health Hubs to improve this.
Best Practice	precise information regarding what to expect and when they should seek urgent help.
What is the impact	
What is the problem	
Topic	

Review Recommendation	should include links to information on how to access baby loss care services 24/7 based on a woman's location and what care they can expect to receive.	5. Each Integrated Care System should introduce a pre-24-week baby loss support and advice line that is available 24/7. We suggest that regions work together to pool resources, as a network approach may be more cost effective. Where possible this could be integrated into existing telephone helplines, or maternity helplines. The advice lines will be able to provide crucial advice and support. Patients can then be referred to the most appropriate department for treatment and care at a suitable time. Being given an appointment at an Early Pregnancy Assessment Unit for the following day could save an individual a	555555555555555555555555555555555555555
Ways in which best practice could be achieved			
Best Practice			
What is the impact			
What is the problem			
Topic			

Review Recommendation	late-night trip to A&E. The CQC should monitor that the advice lines have been implemented, governed and properly maintained.	6. Information leaflets, bereavement support books and bereavement resources should be available to bereaved parents to take home, in all primary and secondary healthcare settings, following a pre-24-week baby loss. Leaflets must be available in all languages and in Easy Read and digital formats.	7. Bereavement care training and education and training in breaking unexpected bad news should be mandatory for all clinical and non-clinical staff working in areas where baby loss occurs. The exception to this should be when an appropriate level of competence can be demonstrated. The training should include
Ways in which best practice could be achieved			Mandatory training is essential for every healthcare professional responsible for breaking bad news to parents, unless competency can be demonstrated.
Best Practice			Every healthcare professional responsible for delivering unexpected bad news regarding pre-24-week baby loss should be adequately trained to ensure that the information they are giving is delivered compassionately. This training will not only help the bereaved parents but will also
What is the impact			Heart-breaking news can at times be delivered insensitively and in a way that may cause additional trauma to the patient.  Families have reported their distress at being told that their baby had died without empathy. On some occasions, the healthcare professional failed to
What is the problem			Many healthcare professionals have shared that they feel illequipped to deliver unexpected bad news to patients.
Topic			Education, Training and Information (Healthcare Professionals)

ch best Review Recommendation uld be ed	experiential personal accounts demonstrating the emotional impact of baby loss, and it should show how compassionate and excellent clinical care can make a substantial difference to patients.  Additional training could be delivered via elearning modules through the Workforce, Training and Education directorate of NHSE, or ideally through face to face training sessions.	k loss  Mumes  professionals who may be in contact with anyone experiencing baby loss should receive mandatory training and education in the importance of sensitive communication, to ensure that they are fully equipped to care for patients compassionately. The only exception to this is where staff can demonstrate competency.
Ways in which best practice could be achieved		All pre-24-week loss training programmes and clinical guidelines should include information on using clear, sensitive and parent-led language.
Best Practice	help the healthcare professional feel better equipped to navigate these emotional and complex situations.	Insensitive terminology and medical jargon harm a patient's experience of care. This practice must be urgently addressed by improving the training and education of all staff, beginning in undergraduate education. The language clinicians use should be clear, sensitive and should
What is the impact	even say that they were sorry for the loss and informed the individual very matter-of-factly that there was no heartbeat. This lack of empathy in delivering unexpected bad news is not acceptable.  Healthcare professionals also reported to us that they often felt like they were letting patients down, due to a lack of training.	Using insensitive language compounds, the distress already being experienced by the patient. The inaccurate connotation of words like 'abortion' and 'products of conception' when referring to baby loss cannot be underestimated.  Feedback from parents
What is the problem		Insensitive terminology and medical jargon both have a negative impact on patients.
Topic		Education, Training and Information (Healthcare Professionals)

Review Recommendation	encouraged to be 'patient-led' in their terminology. This could be delivered via e- learning modules through the Workforce, Training and Education directorate of NHSE. The GMC and NMC should instruct all medical schools, universities and education providers to include this training in the syllabuses.	9. Funding must be allocated to allow NHS England to increase the current investment in NHS staff training to ensure that time is protected for all staff to undertake mandatory annual training in bereavement care for all loss, including pre-24-week baby loss, which will ensure staff can access training during work hours.
Ways in which best practice could be achieved		Some training resources and modules are currently available via e-learning modules through the Workforce, Training and Education directorate of NHSE. Further training opportunities should be developed, including face to face training.
Best Practice	used by the parents. For example, the term 'failed pregnancy' and 'failed abortion' should no longer be used to refer to a miscarriage, and 'products of conception' should not be used to refer to a baby.	Bereavement care training and education should be included in the undergraduate and post-graduate training specifications for all clinicians, including midwives, doctors and nurses. Additionally, bereavement care training should be mandatory for all healthcare professionals and staff who care for or may come into contact with families who experience pre-24-week baby loss.
What is the impact	shows how insensitive and cruel they find this.	Healthcare professionals who lack the essential knowledge and skills required to provide high quality, sensitive and appropriate care and support to families experiencing pre-24-week baby loss often feel overwhelmed and out of their depth This can have a negative impact on the individual's own mental health and can result in a poor care experience for the bereaved families in their care.
What is the problem		Due to a lack of training and education in bereavement care NHS staff reported to us that they feel ill-equipped and lack the confidence and skills required to provide sensitive care and support to bereaved families. Often staff are expected to undertake training in their own time and often at their own expense.
Topic		Education, Training and Information (Healthcare Professionals)

Topic	What is the problem	What is the impact	Best Practice	Ways in which best practice could be achieved	Review Recommendation
	Patients experiencing a pre-24-week baby loss or experiencing either pain, bleeding or both, are made to wait in public areas or be treated alongside pregnant individuals.	This practice negatively impacts the patient experience and also has an effect on the mental health of patients, staff and other patients.	Patients with a suspected baby loss, who are in pain or bleeding should not be made to sit in public waiting areas such as A&E.  Patients experiencing a pre-24-week baby loss should not be expected to sit or be treated alongside pregnant individuals and should only be cared for in maternity spaces at the patient's request or if this is the only	Hospitals and health care providers should ensure that existing spaces are reconfigured to provide private waiting areas/rooms where patients and their partners experiencing loss can be guided to at the point of admission.	10. Funding must be allocated so that each hospital maternity unit, EPAU and A&E department can provide appropriate private spaces for patients experiencing pre-24-week baby loss, that are separate from public waiting areas.
	There is an unwarranted variation in the referral pathway to EPAU's. Some EPAU's will allow self-referral after no losses, while others require a GP, hospital or 111 referral.	The impact of this variation is that people are confused about where to go and due to this lack of clarity, often end up in A&E, which is not the appropriate place for their care.	People booked with a maternity service should initially call their midwife, who may refer them to an EPAU. EPAU's should be the primary place where people between 4-16 weeks gestation should be directed, and it should be much easier to access these services 24/7 than it is currently. Beyond 12-	24/7 access to an Early Pregnancy Assessment Unit could be improved by Trusts and commissioners working in partnership across an Integrated Care System or Region. This approach could also enable more women to access an Early Pregnancy Assessment Unit without a referral.	11. NHS England should develop guidance for commissioners of 111 and ambulance services that sets out how to work with Trusts to contract appointments with EPAUs so that patients with pre-24-week complications can be sent directly to an EPAU when appropriate. This practice already happens in some areas but not everywhere.

Topic	What is the problem	What is the impact	Best Practice	Ways in which best practice could be achieved	Review Recommendation
			16 weeks gestation, women will be cared for in gynaecology or maternity units because they have the facilities needed for the care required.  We are aware of 3 hospitals (UHCW, Heartlands and UCHL) that have created a pathway for ambulances to take patients directly to EPAU rather than to A&E. This has been highly successful and should be a model adopted nationally.	The model created by the three hospitals works on the basis that patients are taken to EPAU by emergency services. Two of the units are open 24/7, and one is not. When the unit is available 24/7, ambulances will always take patients to EPAU. When a unit has restricted opening times, ambulances still take patients to A&E when the EPAU is closed.	12. All areas with an EPAU should receive clinically stable patients directly from the ambulance service during opening hours.  13. People should be able to self-refer to an EPAU with any pain or bleeding during pregnancy, regardless of their gestation, or whether they have a history of previous losses.  14. The RCN and RCOG should build on the 'Nursing Workforce Standards', and expand the current work being undertaken by the RCOG in relation to safer care in maternity services, to develop a workforce planning tool, similar to the 'Birthrate Plus Acuity Tool' for midwives. This would allow safer and more consistent staffing for FPAUs
Service Provision:	EPAU centres are not available at every	Women need to be made aware of where	All women should have access to high-quality	More EPAUs should be established in	15. The National Institute for Health Research (NIHR)

best Review Recommendation	
Ways in which best practice could be achieved	
Best Practice	'Regional services should be organised so that an early pregnancy assessment service is available seven days a week for individuals with early pregnancy complications, where scanning can be carried out, and decisions about management made.'  Early pregnancy assessment services should accept self-referrals from individuals who have had one miscarriage or a previous ectopic or molar pregnancy.  All other individuals experiencing either pain or bleeding or both should be assessed by a healthcare professional (such as a GP, accident and emergency [A&E] doctor, midwife or nurse before referral to an early pregnancy
What is the impact	
What is the problem	
Topic	

Review Recommendation	18. A minimum time allocation of 30 minutes per appointment within an EPAU should be implemented.	19. Gynaecology services must be prioritised by each NHS trust, including the ring-fencing of dedicated gynaecology beds co-located in one area, on female-only wards, and funding must be allocated for this.
Ways in which best practice could be achieved	Appointments must be extended to 30-minutes.	By increasing the number of gynaecology beds in hospitals that have gynaecology wards or services, and increasing the number of gynaecology trained staff, will help to address the imbalance.
Best Practice	Patients should not be rushed. They should be afforded sufficient time to receive appropriate, high-quality clinical care and compassionate emotional support. Pre-Covid, the appointment times were 20 minutes per patient, which healthcare professionals stated needed to be longer. During the Covid-19 pandemic appointment times were extended to 30 minutes, which allowed more time to provide the compassionate care required. This has reverted back to 20-minutes in many areas.	NHS England should prioritise Gynaecology services, ensuring that patients have access to a local hospital.
What is the impact	Because of insufficient time being allocated for appointments, healthcare professionals reported to us that they have not been able to provide the standard of bereavement care they would have liked to have offered.	The impact of this is that women who require inpatient treatment, are being cared for in mixed wards that lack private rooms or adequate facilities. One hospital reported that due to the Gynaecology ward
What is the problem	Patients have not been afforded appropriate time within appointments for clinical assessment, treatment, and mental health screening.	Many hospitals have removed Gynaecology wards and dedicated beds in their hospitals.
Topic	Service Provision: Early Assessment Units (EPAUs)	Service Provision: Gynaecology Services

Review Recommendation	20. Each ICB must provide a Gynaecology Day Assessment Unit that is accessible all day, 7-days a week. This should ideally be attached to or be near to an EPAU. The units should be staffed by specialist gynaecology staff with the ability to scan when necessary.	Funding must be allocated for this.	21. Women experiencing pre- 24-week baby loss should never be cared for in mixed wards with shared facilities.	22. Women experiencing pre- 24-week baby loss should be cared for by specialist healthcare professionals who have received mandatory training in bereavement care and	resources are currently available within the elearning modules through the Workforce, Training and Education directorate of NHSE, and we would
Ways in which best practice could be achieved					
Best Practice					
What is the impact	being removed, anyone experiencing pre-16-week baby loss is being cared for on any ward that has space available, this includes mixed wards with only one toilet available to all male and female patients.	The impact of closing gynaecology wards, results in specialist	gynaecology start being redeployed or leaving the hospital altogether.  By treating patients on non-specialised wards,	worner are more likely to be cared for by healthcare professionals without the specialist skills in bereavement care or gynaecology.	There is an increase in patient complaints to PALS, due to poor care experience.
What is the problem					
Topic					

Review Recommendation	welcome the development of more.	23. NICE must be urgently commissioned to update their early loss: Ectopic Pregnancy and Miscarriage: Diagnosis and Initial Management (NG126) to allow NHS England, to create a pre-24-week baby loss programme and plan for service development and commissioning, to ensure that all updated guidelines are embedded into clinical care. This will then allow each ICS to create a local pathway based upon local needs. Key objectives would be to ensure consistency around clinical care, mental health support, investigation and standards of care, offered to all women. The guidelines must include the following:
Ways in which best practice could be achieved		Standardising clinical guidelines for pre-24- week baby loss would ensure consistency around clinical care, mental health support, investigations and standards of care.  The establishment of specialist support services such as the new Early Pregnancy Loss (EPL) nurse role at Doncaster and Bassetlaw Teaching Hospital, could help to provide the post loss support that is necessary.
Best Practice		All women experiencing loss, including those In subsequent pregnancies, should have access to high-quality physical health care provided by healthcare professionals who are fully equipped to support them both physically and emotionally
What is the impact		Due to variations in the standard of care provided, patients are often left with a negative care experience.
What is the problem		Patients currently experience a considerable variation in the quality of clinical care offered by each hospital. Furthermore, there are also variations in the care provided by each department and each healthcare professional.
Topic		Clinical Care Quality: Physical Health Care

Review Recommendation	If a home pregnancy test reveals a positive pregnancy result 3-weeks following a baby loss, or pregnancy or loss symptoms persist, further medical management should be offered to the individual. This may include a clinical review, repeat urine tests, blood tests to check for pregnancy hormones and/or an ultrasound scan.  Clear integrated care pathways must be established across primary and secondary care which must include the updating of IT systems, to allow communication with GP's IT systems to safeguard	that GPs, community midwives, and health visitors are notified of a baby loss as soon as it occurs.	<ul> <li>If individuals experience a pre-24-week baby loss, and request an</li> </ul>
Ways in which best practice could be achieved			
Best Practice			
What is the impact			
What is the problem			
Topic			

Review Recommendation	appointment with their GP practice, a person-	should be offered to	them. If appropriate or	requested by the individual, their emotional	health and/or implications	for future pregnancies	should be discussed. Information about the	impact on mental health	and trauma that may	ensue following a baby	loss should be provided,	and individuals should be	advised that they can	Therapies. Clinicians	should actively encourage	this self-referral if they	individual.	24. The provision of primary	and secondary baby loss	audited and evaluated by	the ICS. This should be	standard created by NICE
Ways in which best practice could be achieved																						
Best Practice																						
What is the impact																						
What is the problem																						
Topic																						

Review Recommendation	based on their updated guideline.  25. Pregnancy after loss clinics should be established in each hospital offering maternity care. These should be staffed by specialist gynaecology nurses and/or midwives and led by a consultant. When a family is expecting a baby following loss, additional clinical and emotional support is often required, and by offering specialist support, individuals feel heard and understood.  26. To assist healthcare professionals in the care that they provide, and to prevent individuals having to continually share their experience of loss, a new standardised 'Baby Loss Lanyard' should be produced and made available to women through the community midwife, A&E or EPAU.
Ways in which best practice could be achieved	
Best Practice	
What is the impact	
What is the problem	
Topic	

Review Recommendation	We have included a lanyard within the 'CCC Kit' recommendation (rec 38), but this also needs to be separately available for those who are not given a kit.	27. We recommend that further research, evaluation and piloting is required to develop screening tools and pathways for women and their partners suffering with mental health illness, as a result of baby loss. Studies have demonstrated a link between baby loss and PTSD and depression, which in some cases has resulted in suicide.  28. We recommend that psychological support for pre-24-week baby loss must focus on both parents (not just the mother). The importance of the partner's mental health as a potentially integral element of the mental wellbeing of a bereaved couple or family
Ways in which best practice could be achieved		A comprehensive restructuring of current provision to ensure it is extended to people who experience pre-24-week baby loss, and that it is easily and quickly accessible.
Best Practice		Women and their partners should be offered support following a loss, and this should be quickly available to them if they request it.  Letters of acknowledgement and with details of support organisations should be sent to any patient who has experienced any baby loss, who has notified their GP practice. Dr Natasha Hulson, a GP from Leeds Bereavement Toolkit for GP's, which included a letter of acknowledgement and listed support organisations, so
What is the impact		People struggle in isolation and have reported that their mental health has got increasingly worse in the months and years following their loss.  They have also told us how their baby loss was often the first trigger of other mental and emotional health struggles, and how they felt that early intervention would have made a considerable difference to them and their family.
What is the problem		Currently, very little if any mental health support is offered to women and their partners who experience pre-24-week baby loss. Families have repeatedly told us of their struggles with mental health, and their desperation for support.
Topic		Clinical Care Quality: Mental Health Care

Review Recommendation	during and following baby loss, should be recognised and acknowledged more widely.	29. Current mental health provision for individuals following pre-24-week baby loss is insufficient and must be improved to ensure support is easily accessible for anybody who needs it.	30. All healthcare professionals caring for women and their partners who have experienced a baby loss must be made aware, through education	and training of the psychological impact of baby loss and the increased risk of PTSD	and suicide. This could be delivered via e-learning modules through the Workforce, Training and Education directorate of NHSE.	31. Where any healthcare professional believes an individual needs
Ways in which best practice could be achieved						
Best Practice	people knew where to access support.					
What is the impact						
What is the problem						
Topic						

Review Recommendation	evidence-based psychological therapy, a referral must be made to the Perinatal Mental Health team. Confirmation that the referral has been received must be given.  32. When a GP or GP practice is informed that a patient has experienced a baby loss, a letter of support detailing national baby loss support and counselling support and counselling support organisations should be posted or emailed, if the patient has given consent for correspondence. This is to ensure that the patient knows that their loss has been formally acknowledged and that they have access to details of support organisations. A template is included in Annex G.	33. The National Institute for Health Research should commission research into pain management for pre-24-week baby loss, as our research has shown
Ways in which best practice could be achieved		Develop new guidance and training to ensure patients experiencing pre-24-weeks baby
Best Practice		Patients experiencing baby loss should be offered sufficient analgesia alongside anti-emetics.
What is the impact		Patients are experiencing unnecessary pain and distress, which adds to the trauma of loss.
What is the problem		We were told by many patients that they were not offered adequate analgesia. The RCOG early miscarriage information leaflet (PIL)
Topic		Clinical Care Quality: Analgesia

Review Recommendation	that patients are often left without suitable or sufficient pain relief.  34. The Royal Colleges of Obstetricians and Gynaecologists, Nursing, Midwives and GPs should develop resources and information to ensure support for healthcare professionals regarding using analgesia and antiemetics for anyone experiencing a pre-24-week baby loss.	35. We must have an enforceable guideline or regulation (in line with the HTA Guidance) surrounding the sensitive disposal of pre-24-week babies, and baby loss remains.  36. The NHS in partnership with us, should develop and deliver an appropriate and sensitive receptacle to collect baby loss remains when a person miscarries.
Ways in which best practice could be achieved	loss are not needlessly suffering.	Ensure that Human Tissue Authority (HTA) guidelines on handling and transporting the pregnancy remains/baby are consistently followed. The following of these guidelines is vital, given the significant variation amongst Trusts (and in some cases within a single hospital). Robust mandatory training programmes for staff and close collaboration with teams such as the
Best Practice		Pregnancy loss remains should be handled respectfully following the Human Tissue Authority Guidelines. Using bedpans, kidney dishes or sanitary towels to lay babies onto is unacceptable. If a miscarriage occurs away from a clinical setting (e.g. at home), the parents should not have to:  Use household receptacles to store the remains.
What is the impact		Healthcare professionals have to provide patients with bedpans and similar receptacles to use during baby loss.  Due to the absence of suitable containers, patients are asked to store their babies, or pregnancy loss remains in plastic containers and keep them in their fridges until hospital departments are open
What is the problem	and NICE guideline on ectopic pregnancy and miscarriage (NG126) both state that women should be offered pain relief and anti-sickness medication, however, many patients reported to us that they were given insufficient medication or were not offered any medication at all.	Currently, the NHS does not have any standardised receptacle for the delivery into and storage of babies or baby loss remains. In addition, hospitals will often not accept baby loss remains outside of standard hours.
Topic		Clinical Care Quality: Sensitive Handling and Storage of Remains

Review Recommendation	<ul> <li>37. The NHS in partnership with us, should develop and deliver an appropriate, respectful container where baby loss remains may be stored, following a miscarriage.</li> <li>38. We are currently working to develop a 'Baby Loss Kit' called the 'CCC Kit' (Compassionate Clinical Care Kit), to be provided to women when a miscarriage is expected or likely to take place in a home setting or in a clinical setting. The 'CCC kit' should comprise a receptacle and container to collect and store the baby's remains, clear instructions for the baby's remains, clear instructions for the clinician regarding how to explain the use of the kit to the woman (e.g. using patient-led language), clear instructions for the woman on what to do, what to expect, and should include emergency contact details. Ideally, the kit would also include a</li> </ul>
Ways in which best practice could be achieved	ensure this.
Best Practice	Store the remains in their household refrigerator until services re-open.     Hold their baby's remains or wait for a second ambulance to collect the remains if being transported to the hospital by ambulance.
What is the impact	to receive delivery of them. It is distressing for staff to advise bereaved parents to do this.
What is the problem	
Topic	

Review Recommendation	lanyard that a person could wear when accessing help or support in any clinical setting, so medical staff are aware of their previous or current loss. The 'CCC kit' should be available from all NHS hospitals, GP practices, community health services, pharmacies, etc. The 'CCC kit' should be offered to people who are pregnant again following a previous loss.	39. EPAUs and A&E's should ensure that cold storage facilities (e.g. a dedicated refrigerator) are available to receive and store baby remains / pregnancy tissue 24/7, so that people aren't asked to store them in their home refrigerators.	40. Each NHS Trust should offer a choice of personalised, individual or communal funeral services to all individuals who experience pre-24-week baby loss. All
Ways in which best practice could be achieved			
Best Practice			
What is the impact			
What is the problem			
Topic			

best Review Recommendation be	parents should be given the opportunity to attend their baby's funeral, whichever type of funeral they choose.	41. Each NHS Trust and Integrated Care System should establish a clear clinical pathway (based on the British Association of Perinatal Medicine (BAPM) Guidelines and Together for Short Lives Perinatal Pathway for Babies with Palliative Care Needs) for pre-24-week gestation babies born with signs of life that encourages professionals to work together across multidisciplinary teams and local services to provide sensitive parent-centred end of life care, enabling families to spend time with their baby, and create precious memories.  42. To reduce regional variations in neonatal death rates, all clinicians caring for women and babies born before 24
Ways in which best practice could be achieved		Having dedicated bereavement leads coordinating and overseeing the provision of appropriate, palliative, end-of-life and bereavement support for families.  Bereavement leads networking across an Integrated Care System or another geographic region would help to standardise care across services.
Best Practice		Babies born with signs of life before 24 weeks gestation with no prospect of survival, should receive appropriate palliative and end-of-life care.
What is the impact		This results in confusion for healthcare professionals which may result in decisions being made without a clear understanding of current best practice recommendations.  Parents are often left confused as to whether the best decisions were made for their babies and can question if their baby had been treated in a different hospital or trust, the results would have been different. This ambiguity opens up the NHS to criticism, complaints and litigation.
What is the problem		Healthcare professionals often have limited training or education around the importance of appropriate perinatal palliative and end-of- life care.
Topic		Clinical Care Quality: Palliative Care

Review Recommendation	weeks gestation should be required to undertake training in the MBRRACE-UK (Mothers and Babies, Reducing Risk through Audit and Confidential Enquiries) national clinical guidance for the 'Determination of signs of life following spontaneous birth before 24+0 weeks of gestation' where, following discussion with the parents, active survivalfocused care is not appropriate. Whilst this clinical guidance has been in place since 2020, there is still much confusion and inconsistency in its delivery.	43. Working with the Royal Colleges, NHS England should develop standardised primary and secondary care clinical guidelines for pre-24-week baby loss, and the RCOG should further revise their Green-top Guidelines, so that local service providers and
Ways in which best practice could be achieved		The development of a clear guideline for hospitals and primary care trusts to follow will help to eliminate disparities in the options available to patients. The guideline would need to be flexible enough to accommodate
Best Practice		Women who experience recurrent miscarriages should be able to access care from an appropriately trained specialist consultant obstetrician/gynaecolog ist. They shouldn't have to wait until they have had three recurrent
What is the impact		Some losses could be prevented by earlier identification of issues. By not allowing tests until three losses have occurred, clinicians are unable to identify and manage health care issues and conditions,
What is the problem		Women often have to experience three consecutive baby losses with no live births before they are offered testing and investigations. There is also inconsistency locally and nationally, i.e. some trusts and health care providers
Topic		Clinical Care Quality

Review Recommendation	update their local guidelines and service provision. The guidance should include:  • Following the first loss, if individuals experience a pre-24- week baby loss, and request an appointment with their GP practice, a person- centred consultation should be offered to them. If appropriate or requested by the individual, during this appointment the individual's baby loss experience and future pregnancies should be discussed. Information about the impact on mental health and trauma that may ensue following a baby loss should be ababy loss should be provided, and individuals should be advised that they can self-refer to NHS Talking Therapies. Clinicians should actively encourage
Ways in which best practice could be achieved	individuals' personal factors, e.g. maternal age or those with a history of infertility.
Best Practice	miscarriages for a specialist consultant referral.
What is the impact	some of which may be easily treatable. In addition, unimaginable pain and suffering could have been avoided with earlier intervention. Sadly, many relationships break down following a single baby loss, and repeated loss may further damage relationships. Relationships Relationships breakdown has a severe impact on family structures and mental health.
What is the problem	are more flexible. This creates a postcode lottery of care and practice.
Topic	

Review Recommendation	this self-referral if they feel it would benefit the individual.	<ul> <li>Following two losses,</li> </ul>	an appointment should be made for	blood tests, including	full blood count and thyroid function and	other necessary	investigations.	Depending on the	results of these tests,	along with any other	pre-existing or chronic	physical or mental	health conditions,	referrals should be	made to the relevant	specialism.	<ul> <li>Following a third baby</li> </ul>	loss, a consultant-led	appointment should	be offered, at a	specialist recurrent	miscarriage centre	where possible, so	additional tests,	including genetic	testing, scanning,	screening and	treatment, may be	
Ways in which best practice could be achieved																													
Best Practice																													
What is the impact																													
What is the problem																													
Topic																													

Review Recommendation	The standardised primary and secondary care clinical guidelines should include flexibility to accommodate and prioritise factors such as advanced maternal age, fertility, recurrent loss, and other medical conditions.	44. Individuals recognised as high-risk for baby loss at their booking appointment or at any time during pregnancy should receive personalised care pathways, which may include a higher level of care and monitoring.	45. Specialist recurrent loss clinics should be developed in each region and offer a holistic service approach.	46. We recommend that an NHS-wide flag system should be implemented, so that pre-24-week baby loss can be highlighted on parent's patient notes. This will help healthcare
Ways in which best practice could be achieved				
Best Practice				
What is the impact				
What is the problem				
Topic				

Review Recommendation	professionals to be aware of any previous losses and assist them in providing a compassionate and sensitive care experience, without the individual having to repeatedly recount their story of loss. This should work in tandem with the lanyard recommendation (rec26).	Council (GMC) should look to introduce credentials in Early Pregnancy Loss, and the RCOG and BGSE should consider the opportunities to improve the specialist training pathway in Early Pregnancy Loss.	48. The RCOG and the AEPU should review training opportunities in Early Pregnancy Loss, Emergency Gynaecology, Prenatal Diagnosis, and Recurrent Loss to ensure they meet the need for specialists in this area 49. In a subsequent pregnancy, an early
Ways in which best practice could be achieved			
Best Practice			
What is the impact			
What is the problem			
Topic			

Review Recommendation	reassurance scan should be offered and the woman and her partner should be signposted by the midwife to appropriate services for ongoing emotional support and psychological support, help manage anxiety levels.	50. There should be a review of guidance and training modules for all current and future ambulance staff, to ensure they are mentally equipped and appropriately trained in the management of pre-24-week baby loss. Where a training deficit is identified, this should be immediately addressed and protected time to attend additional training should be sanctioned.
Ways in which best practice could be achieved		All ambulance staff should attend training in pre-24-week baby loss management, as part of their basic training, or retrospective training for existing personnel, based on the BAPM Framework for Practice - Pre-hospital management of the baby born at extreme preterm gestation (https://www.bapm.org/resources/pre-hospitalmanagement-of-the-baby-born-at-extreme-preterm-gestation) in addition annual mandatory training in bereavement care and support should be given to ensure
Best Practice		All ambulance staff should receive mandatory training in pre-24-week baby loss management. All individuals should feel emotionally, mentally and clinically prepared to deal with all pre-24-week baby loss situations. They should not be expected to undertake this training in their own time.
What is the impact		The impact is two-fold:  1) Ambulance crews are often left traumatised as a result of attending pre-24-week baby loss. This is compounded by the lack of training they have received in having to make decisions about the management of the baby, (when often the gestation is unknown) whilst simultaneously
What is the problem		Ambulance crews are often the first responders to medical emergencies involving baby loss, yet they undertake very little training and education in the management of unexpected pre-24-week baby loss and the care of parents facing these tragic circumstances.
Topic		Clinical Care Quality

Review Recommendation		51. We understand that hospitals are limited in their capacity and workforce to perform surgical terminations and the majority of patients undergoing a TFMR are referred to the independent sector, therefore it is imperative
Ways in which best practice could be achieved	consistency of compassionate care. Staff should be regularly updated on current local and national guidance to ensure consistency in care delivery.	All NHS and independent providers must have ccarefully coordinated pathways in place for women and their partners undergoing TFMR
Best Practice		All NHS funded services must ensure that patients receive high-quality experiences of care.
What is the impact	clinical care to the mother who may not be clinically stable.  2) Due to the lack of a clear pathway parents are often left questioning whether their baby's death could have been prevented if the delivery had happened within a hospital setting.	The impact is that patients are often referred to clinics that are not always physically able to accommodate the following:  The separation of those who are
What is the problem		Currently, the majority of patients who opt to have a surgical termination following a diagnosis of a fetal anomaly, will be required to have the procedure performed by an independent service provider.
Topic		Clinical Care Quality: Terminating for Medical Reasons – Independent Providers

Review Recommendation	that all providers have robust protocols and pathways in place for TOPFA patients. The NHS and independant providers must have carefully coordinated pathways in place for women and their partners undergoing TFMR. Hospitals and independent service providers should seek to ensure that the partners of-patients undergoing a termination can attend the appointment at the clinic if this is what the patient requests. Excluding partners from what can be an equally distressing experience for both partners is unacceptable. Where possible, people experiencing a TFMR should not be cared for alongside patients who are choosing to end an unwanted pregnancy.	52. Further oversight and governance of the profession of Sonography is essential to ensure that patients are offered safe
Ways in which best practice could be achieved		Official regulators should regulate private ultrasound scan centres.
Best Practice		People seeking reassurance or souvenir scans from private clinics should be able to trust that
What is the impact	ending an unwanted pregnancy and TFMR patients.  The inclusion of partners through all appointments and the procedure.  In addition, clinic staff vary in the level of training they have received in order to support TFMR patients.  Parents report that attending independent clinics causes them trauma and pain, and their emotional needs are not met.	People can be given false reassurance following a scan. The impact of this is that they do not access
What is the problem		Private scanning facilities are unregulated, meaning that anyone can set up a clinic without the
Topic		Clinical Care Quality: Sonography

Review Recommendation	and compassionate care. We are aware of the impending report from the Society of Sonographers that supports this. We therefore recommend that all sonographers should hold a UK qualification from the Consortium for the Accreditation of Sonographic Education or overseas equivalent, as called for by the British Medical Ultrasound Society (BMUS).	53. All sonographers who may need to break unexpected bad news to parents should be required to undertake training on 'Consensus Guidelines on the Communication of Unexpected News via Ultrasound'  (UK consensus guideline s for the delivery of unexpected news in obstance of the delivery of unexpected news in obstance of the courses to develop their skills.
Ways in which best practice could be achieved		All sonographers undergo national or regional training.
Best Practice	their sonographers be qualified and regulated.	All sonographers are trained in breaking unexpected bad news.
What is the impact	necessary medical help or intervention Additionally, many people are not offered any emotional support (if a loss is diagnosed).	Additional trauma for bereaved parents
What is the problem	skills and training to correctly scan and support individuals during their pregnancy.	Patients report a lack of compassion and care in the breaking of unexpected bad news by sonographers, which adds to the trauma of the loss.
Topic		Clinical Care Quality: Sonography

Review Recommendation	54. The National Institute for Health Research should commission additional research into why there is an increased risk of pre-24-week baby loss in women from Black, Asian and ethnic minority backgrounds and in people from socioeconomically deprived areas, and what may be done to minimise those risks.  55. National and local guidance should be developed to sensitively address the varying support needs of people who experience a pre-24-week baby loss resulting from alternative routes to parenthood, such as adoption and surrogacy.
Ways in which best practice could be achieved	Conducting thorough research into the levels of loss encountered by different ethnic, socio-economic and other groups will allow targeted support, care, and pathways to be developed specifically to target disparities. In addition, all pre-existing pathways must include access/support for these groups and acknowledge and respond to their individual needs.
Best Practice	There is a need to better understand and respond to the causes of disparities in the care and outcomes for people of different ethnic, and socioeconomic backgrounds.
What is the impact	a. Data shows that there is a greater risk of baby loss for Black, Asian and Ethnic Minority groups, which results in increased trauma and fear in subsequent pregnancies for individuals from these backgrounds (Quenby S, Ioannis D Gallos I D, Dhillon-Smith RK. Miscarriage matters: the epidemiological, physical, psychological, and economic costs of early pregnancy loss. Lancet 2021; 397: 1658–67).  b. There is an increased risk of loss and fear for individuals from these groups. Therefore, there is an increased need for primary and secondary care
What is the problem	a. Ethnic Disparities: There is an increased risk of baby loss for people from Black, Asian and ethnic minority groups. Black women are 43% more likely to experience a miscarriage than a white woman <sup>111</sup> .  b. Ethnic Disparities: Poor communication from healthcare professionals, language barriers, racial bias, and a lack of research & data all contribute to women from Black, Asian and minority ethnic groups having a poorer care experience and may deter patients from engaging with healthcare services.  c. Socio-economic background
Topic	Clinical Care Quality: Addressing Disparities

l best Review Recommendation d be		into 56. We support the Law Commission's proposal on creating a new surrogacy pathway that will allow, the intended parents to be the legal parents of the child from the moment of birth and recommend that this includes from the moment that baby loss occurs.  This would eliminate the multiple obstacles faced by surrogate parents when arranging funeral/cremation services. Support for the intended parent and the surrogate mother should be offered.	ital 57. NHS England must increase capital am. investment to ensure adequate facilities are
Ways in which best practice could be achieved		Further research into the experiences of surrogates and intended parents.	Each NHS Hospital should appoint a Bereavement Team. The reason we are
Best Practice		There is a need to better understand and respond to the causes of disparities in the care and outcomes for people expecting a baby via a surrogate.	Baby loss is a devastating event often with enduring psychosocial
What is the impact	support within these areas.	Heterosexual individuals who embark on a surrogacy journey often do so following infertility or recurrent loss. If their surrogate tragically experiences baby loss, it often compounds preexisting grief and trauma with fresh sorrow and trauma. Most surrogates and intended parents are overlooked when it comes to being offered support, and the impact is unacknowledged grief, mental and emotional health struggles, and an effect on relationships.	People reported that they sometimes had poor experiences with their primary care
What is the problem	Disparities: People from low-income/deprived areas of England are at a greater risk of loss due to environmental and other factors.	Surrogacy Disparities: The intended parent, is not routinely offered any emotional support following a loss. Additionally, it is often presumed that the surrogate does not need emotional support following a loss as they are not the intended parent.	An estimated 1 in 4 pregnancies will end in loss, resulting in most parents experiencing
Topic		Clinical Care Quality: Addressing Disparities	Bereavement Care & Support

Review Recommendation	provided for bereaved parents. Bereavement suites, counselling rooms, and private spaces should be available to all families regardless of the baby's gestational age. Women and their partners should not be expected to receive unexpected bad news, discuss treatment options, or grieve in public spaces. Funding should be allocated for this.  58. NHS England must focus on recruiting and retaining more specialist gynaecology nurses and bereavement midwives, with equality of banding and pay. These roles are imperative to the delivery of safe and compassionate care to families experiencing loss, however, due to them not being prioritised by all trusts, these roles are chronically underfunded and undervalued.
Ways in which best practice could be achieved	proposing a team rather than an individual bereavement lead, is due to the scale of the role, and the fact that it requires multidisciplinary expertise to create a comprehensive and robust bereavement service, that is not dependent on one person.  NHS and GP Practice staff who come in contact with bereaved individuals should be trained to provide bereavement care and support.  More dedicated facilities for those experiencing loss could be provided.  Bereavement support specialists could work in non-clinical settings such as purpose-built bereavement centres or GP practices to provide emotional support to bereaved families.
Best Practice	consequences for both parents. All individuals and their partners should expect to receive high-quality, personalised, compassionate bereavement care and support regardless of the type or gestation of the loss. All patients deserve an assurance of excellence in the care that they receive. We are unable to prevent all baby loss, but what we can do, is ensure that the care that the care that they receive does not cause further trauma.
What is the impact	provider. Their GPs and other healthcare professionals regularly used insensitive language and were not aware of clinical and bereavement care pathways. Without clear bereavement guidelines, it is not surprising that these issues exist.  When people experience inadequate care from primary and secondary care providers, their experiences can often be widely shared in the public domain (via social media and online bereavement groups.) The consequence is that individuals avoid specific hospitals/clinics due to a reputation for uncompassionate care and clinical services. This results in an overburden on other better-performing hospitals or clinicians.
What is the problem	grief and trauma and needing to access both primary and secondary care services for medical or mental health support.  Clinical care can be exceptional in some primary and secondary care systems whilst incredibly poor in others. Disparities can also exist within the same hospital trust and even within the same departments. These disparities are due to the variation in training and education of each healthcare professional. This results in an unwarranted variation in standards of care.
Topic	

Review Recommendation	59. NHS England must ensure that specialist bereavement teams' are established in all hospital trusts to ensure that Best Practice is applied service wide. These teams should include the Bereavement Lead Midwife, Lead Midwife, Lead from EPAU, Lead from A&E (where applicable), Lead Chaplain, Lead of Neonatal, Lead of Neonatal, Lead of Paediatrics, the Trust Bereavement Services Lead, and the Mortuary Manager). The team should meet at least monthly to review cases, share learning and best practice, and develop policies and procedures to create a forward-thinking bereavement service for baby loss at all gestations. This team approach would ensure that regardless of in	which department the loss occurs, the same level of emotional care
Ways in which best practice could be achieved		
Best Practice		
What is the impact	Through our combined experience of over six decades, coupled with the thorough work of this review (including parent panels), we have seen first-hand the ramifications that poor care and support can have on individuals and families, physically, mentally and emotionally.	
What is the problem		
Topic		

Topic	What is the problem	What is the impact	Best Practice	Ways in which best practice could be achieved	Review Recommendation
					and practical support is offered.
					60. All NHS Trusts must
					ensure that they have a
					sufficient number of key staff who are fully trained
					(having undertaken the
					Perinatal PM Consent
					Training Programme <sup>112</sup> or
					similar) in taking consent
					histological and genetic
					testing of early pregnancy
					loss remains, and that
					only these staff should be
					permitted to seek consent
					for a post-mortem.
					Additionally, it is essential
					that they are fully
					conversant with the
					current national and local
					consent processes
					relating to this, to ensure
					considering these
					investigative procedures
					receive high cuality
					information in a timely
					manner. All NHS Trusts
					should monitor this
					training and compliance.
Bereavement Care &	<ul><li>a. Baby loss before</li><li>24 weeks gestation</li></ul>	a. This lack of acknowledgement	All parents should be able to have their loss	NHS Trusts should actively source	61. In recognition of a life lost, the Government
	has historically not		recognised if this is	resources and	must ensure that an

>	What is the problem	What is the impact	Best Practice	Ways in which best practice could be achieved	Review Recommendation official certificate is
been recognised a life lost and has mostly been	ed as		what they request, and all healthcare professionals should	equipment for creating memories rather than relying on charities to	official certificate is available to anyone who requests one after
treated as a clinical incident. A lot has	as	<ul><li>b. In a survey by the Mariposa Trust</li></ul>	support this by offering them the opportunity to	donate them. Additionally,	experiencing any loss pre-24 weeks gestation.
changed in the past 10-15 vears. but	past ıt	(Saying Goodbye) of over 2.600	create memories of their babies.	Bereavement leads in regions could work	The certificate must be back datable with no cut-
we still have a long way to go.	ong	people, 88% of those surveved	Depending on the circumstances.	together to distribute donated equipment	off point, so people with a historic loss may also
		classed having a	healthcare providers	based on need.	access this long-
<ul><li>b. When a loss occurs after 24 weeks</li></ul>	cours	certificate as important or very	may offer items such		requested recognition. This certificate must be
gestation parents	ıts	important to them.	tags, sensitive		available to anyone
are either given a	عاد و	They stated that it	photography, and		regardless of the type of
or birth and death	ath	significant	there are no baby loss		experienced. Parents
certificates (if the	ЭC	difference to them.	remains, parents		must have the option to
baby has been	,	Surveys by SANDs	should be given		be able to supply
born with signs of	o >	and The Miscarriage	information regarding		evidence of loss, but this should not be mandatory
loss occurs pre-24	-24	Association further	commemorative		The wording on the
weeks without		endorsed the	certificates, support		certificates should be
signs of life, the	0	importance of	books and memory		adaptable (including an
parents receive no official certificate.	<u>2</u> 6	certificates to families.	DOXES.		option to add a baby s name), as it is vital that
To fill the gap,					parents are able to
charities and		c. The impact of			choose the language they
hospitals have		memory-making			prefer. The certificate
made		not being available			should be available as a
commemorative	d)	to all is that many			download or as a hard
available Still		Johnson of their			needs to be accessible by
parents widely		opportunity to			all, not just by people with
report that this is	<u>.s</u>	create precious			access to a computer;
unsatisfactory and	and	memories of their			This also needs to be

Review Recommendation	available to both parents.  To ensure the certificates remain credible, the applicant should be required to provide ID verification. The certificates will not be legal certificates will not be legal certificates but will be official governmentissued ones, and should look official, rather than just commemorative, as it is crucial to families that they have official recognition of their loss. We will continue to partner with the Government to design and deliver this as quickly as possible.
Ways in which best practice could be achieved	
Best Practice	
What is the impact	baby. Not being offered the opportunity to create memories can cause considerable emotional distress which cannot be remedied in the future.  d. Due to the NHS not supplying memorymaking kits, hospitals are forced to source their own memory-making materials from charities. We heard that some hospitals have an abundance of supplies, whilst others have none. Furthermore, if the charity that supplies a hospital ceases to operate, the hospital loses its ability to provide these valuable resources to families.
What is the problem	does not give them the official recognition they long to have.  c. Memory-making has become commonplace in most hospitals; however, this needs to be improved outside of maternity departments. It is essential that memory-making is offered to all parents, regardless of where the loss occurs, whether this is in a primary or secondary care setting or within their own home.  d. Memory-making kits are nearly all supplied to hospitals by charitable donations, and hospitals should not have to rely on charities to be able
Topic	

Review Recommendation		62. All bereavement support services provided by each NHS Trust and healthcare provider must ensure that the spiritual and cultural care needs of each patient are met, and that hospital chaplaincy/pastoral services are offered to all individuals and their partners experiencing loss regardless of the type of loss or gestation.  63. A Primary Care Chaplaincy/Pastoral service has already been trialled in multiple areas including Birmingham, Dudley and across Scotland. GP's are able to socially prescribe listening services to patients. This should be rolled out across all Primary Care nationally.	64. NHS England should issue guidance to all staff on using electronic patient records systems regarding the recording of
Ways in which best practice could be achieved		Hospital chaplaincy services offering pastoral/spiritual support should work closely across all departments where baby loss occurs.	Ensure that NHS IT systems are fit for purpose and linked. A clear notes system should be implemented
Best Practice		Spiritual and pastoral care should be offered to all bereaved parents and families, along with the opportunity to hold cultural and religious ceremonies and rituals, such as a blessing, funeral or remembrance service. Healthcare professionals should respect cultural and religious preferences and adopt a flexible working approach to meet individual wishes.	The NHS has systems to ensure that a baby loss is entered into a patient's medical records.
What is the impact		At one of the worst times in a person's life, they feel they must fight for their beliefs to be acknowledged and recognised by those caring for them.	This results in people receiving appointments and reminders for scans and other monitoring after the
What is the problem	to offer this service to parents.	Baby loss occurs across every sector of society and every religious group. Having met with various religious groups through the work of the review, including people from the Muslim, Christian and Orthodox Jewish communities, all have expressed concerns that their beliefs, customs and rituals are often not acknowledged or respected.	When a person experiences loss, the IT system across England often fails to
Topic		Bereavement Care & Support: Primary and Secondary Care Chaplaincy	Patient Records, IT & Data:

Review Recommendation	pre-24-week baby loss. The data fields for recording such losses and generating notices to other electronic patient notes systems (e.g. GP patient records) must be made mandatory to prevent patients from being notified of outstanding maternity appointments and scans in error. We understand that this is a long-term objective rather than something that can be achieved easily and quickly, but this must be prioritised in the current digital transformation	65. People should be able to inform their GP that they are pregnant or that they have had a pre-24-week baby loss via apps such as MyNHS or MyGP or an alternative simple system. The system should trigger push notices to ensure the patient receives relevant information regarding pregnancy, baby loss, mental health
Ways in which best practice could be achieved	across England to support the smooth transition of information across all departments. A person's loss history must be highlighted on patient notes (digital or paper) so all staff know about the loss at the start of every appointment.	
Best Practice	The record of loss should be flagged, so that future maternity appointments are cancelled automatically, clinicians are aware of their patient's history, and the patient doesn't have to tell their story over and over again.	
What is the impact	pregnancy has ended. Parents report that this causes them additional distress and makes them feel that the NHS does not understand the impact of their loss.	
What is the problem	update all patient records.	
Topic	Recording of Data	

What is the problem What is the impact
Data does not have to be recorded, be recorded concerning have to be recorded, healthcare professionals are often unaware that someone has experienced a loss when they meet with them. Due to this, support is often not offered to individuals, and families have to recount their losses and experiences repeatedly, which can result in more trauma. In addition, families are often not given any information on risk factors or advice for subsequent pregnancies.  Because data does not have to be recorded concerning a pre-24-week baby loss, the true scale of loss is unknown. The first step to eliminating or reducing a healthcare issue is acknowledging and understanding the

st Review Recommendation	NHSE Transformation Directorate or NIHR should undertake research into the feasibility of pre-12-week data collection.	67. The DHSC should commission NHSE Transformation Directorate to collate and publish monthly data on mid-trimester loss i.e. 12-23+6 weeks gestation.) Monthly reports providing data that can be delivered from existing data sets, should be identified and published as soon as possible.	s 68. All organisations should update their Human Resources (HR) policies and practices to adequately support staff who experience pre-24-the week baby loss. he for
Ways in which best practice could be achieved			Terms and conditions of employment for all employees should stipulate the leave time available for people to seek care and support and to recover from the baby loss whatever the gestation or type of loss.  Information on the leave time available for people to seek care and recover from baby
Best Practice			Employers have a duty of care to all employees when a baby loss occurs, regardless of gestation. People shouldn't have to work whilst they are experiencing a miscarriage or following a loss, and they should be given sufficient time off work to recover both physically and emotionally.
What is the impact	scale; without this, we can only attempt to lessen the problem.		At a time of extreme grief and stress, employees are worried about their jobs. Many people reported to us that they either lost their job or were forced to change careers because of the lack of compassion and care. This financial insecurity and worry is an additional burden for
What is the problem			Currently, some employees are battling with their employers over bereavement leave and pay following early baby loss. Some companies go above and beyond what they are obliged to offer in support of their staff, whilst others offer no flexibility.
Topic			The Workplace: Employers

Review Recommendation		69. The NHS should be a leading example in offering excellent bereavement support and leave to staff who experience pre-24-week baby loss. We recommend that up to 10-days paid leave for the person who is pregnant, and 5-days for the partner should be provided for any pre-24-week baby loss. A 'Fitness for Work' statement from a GP should not be required unless additional time off is required. This paid time off should not be used for 'sickness trigger' purposes. In addition, NHS employees should be offered paid time off for appointments linked to pregnancy or baby loss, and flexible working arrangements should be offered where possible.
Ways in which best practice could be achieved	loss at any gestation should be readily available and easy to find in organisational handbooks and on intranets.	The NHS should have policies to support their staff following a loss at any gestation.
Best Practice		As a caring organisation, the NHS should lead the way in human resource policies concerning leave. Staff should be able to access leave as required.  'The Pregnancy Loss Pledge' launched by the Miscarriage Association is an example of good practice and has been adopted by some employers including 12 NHS Trusts (https://www.miscarriage-and-the-workplace/the-pregnancy-loss-pledge/).  The Mariposa Trust (Saying Goodbye) offer the 'Mariposa Gold Standard' for
What is the impact	grieving individuals and families.	Staff suffering multiple baby losses in a year may require more than three periods of bereavement leave, which can result in the formal sickness absence procedure being triggered.  We heard from midwives and other healthcare professionals about how they were forced to return to work whilst physically bleeding from a loss, as they feared the consequences of having an absence of leave recorded on their employment record.  We heard from distressed staff who had been put on disciplinary measures and how this was often
What is the problem		Currently, all leave for some NHS staff is grouped into one category, bereavement, sickness or parental leave. Staff are only entitled to 3-days of bereavement leave in each calendar year.
Topic		The Workplace: The NHS

Ways in which best Review Recommendation practice could be achieved	70. Each NHS Trust should offer reasonable bereavement leave and remove any restrictions limiting bereavement leave to 3-days per year. 71. NHS Trusts should not group bereavement, sickness and parental leave in the same category.	The NHS should have policies, supervision systems, and services in place to support their staff who care for people experiencing a pre-24-week baby loss who might need support.  The NHS must put adequate mental health support in place for all NHS staff.  The NHS must place for all NHS staff.  The NHS must instruct trusts to offer regular restorative clinical support.  The NHS must place for all NHS staff.  The NHS must place for all NHS staff.  The NHS at aff.  The NHS must place for all NHS staff.  The NHS at aff.  The NHS must instruct trusts to offer regular restoration sessions to staff who are working with loss on a daily basis, examples of which are bereavement midwives and antenatal screening.
Best Practice	employers. This award is presented to organisations that have gone above and beyond in implementing employee-centred policies for anyone affected by baby loss. Some trusts have introduced a wider support package with no limit on the number of episodes a year which is much appreciated by staff.	All primary and secondary care staff praining for parents sexperiencing pre-24- in week baby loss should shave access to mental prealth and emotional proport through staff webriefs, peer support sand clinical supervision.
What is the impact	the final nail in the coffin for them deciding to leave the NHS.	Many staff feel ill- prepared to support patients when they are personally struggling with their own mental health.  There is an increase in periods of sickness and absence, and staff retention suffers as a result of long-term stress and burnout.
What is the problem		Many staff working on a regular basis with baby loss have reported to us that they are suffering from compassion fatigue and other adverse impacts on their mental health due to the lack of support they receive.
Topic		Workplace: NHS Mental Health Provision

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Topic	What is the problem	What is the impact	Best Practice	Ways in which best practice could be achieved	Review Recommendation
		through a lack of acknowledgment of the impact that working with loss on a daily basis has on an individual's quality of life.			anyone affected by their work with pre-24-week baby loss, to help reduce stress and prevent burnout.

# Legal Age of Viability

We initially considered reviewing whether the legal age of viability should be reduced from 24 weeks to 20 or 22 weeks in line with other countries. However, it was decided following an Advisory Panel meeting that this was outside the scope of the Terms of Reference for this Review.

### **Annex B. Terms of Reference**



## The Pregnancy Loss Review: Care and Support when Baby Loss Occurs Before 24 Weeks Gestation

Terms of Reference

March 2018

### Terms of Reference

### **Background**

- 1.1. Many of the care considerations for parents experiencing a stillbirth (when a baby is born without signs of life after 24 weeks gestation) will be similar for those experiencing a miscarriage. Local policies, however, may affect the type and place of care offered or available depending on the gestation when baby loss occurs.
- 1.2. In particular, registration certificates are often greatly valued by some parents as a way of recognising and naming their baby. Currently, parents whose babies are stillborn after 24 weeks gestation can register the baby's name and receive a certificate of registration of stillbirth. When a pregnancy ends before 24 weeks gestation however, there is no formal process for parents to legally register the loss. Some expectant parents find this to be particularly distressing, whilst other parents would find it equally distressing if they were required to register the loss when they did not want to.

### Purpose of the review

- 1.3. The purpose of the review is to consider:
  - The impact on families of the current threshold of 24 weeks gestation before being able, formally, to register a miscarriage if they so wish.
  - Whether it would, on balance, be beneficial to look at legislative options to amend existing primary legislation to allow parents to register a miscarriage if they so wish
  - Options to improve NHS gynaecology and maternity care practice for parents who
    experience a miscarriage and other causes of baby loss.
- 1.4. The review will not consider changing the existing laws on abortion. However, the review's recommendations for improving care and support for those experiencing a pre-24 week gestation baby loss may be relevant to women and families who choose to terminate a much wanted pregnancy, for example due to congenital anomalies.
- 1.5. The review will work with key partners to make recommendations to government. The recommendations will be aimed at improving the care and support women and families receive when experiencing a pre-24 week gestation baby loss.
- 1.6. Some of the solutions are likely to lie in practice rather than in legislation. The review should consider practice-based solutions wherever possible.
- 1.7. The review will help government create a forward-looking approach to improve the support and experience of care for women and families who have a pre-24 week gestation baby loss.

### Leadership and Governance

- 1.8. The co-leads for the review are:
  - · Zoe Clark-Coates, Founder & CEO, The Mariposa Trust; and
  - Samantha Collinge, Specialist Midwife and Maternity Bereavement Service Manager, University Hospitals Coventry and Warwickshire NHS Trust.

March 2018

### The Pregnancy Loss Review: Care and Support when Baby Loss Occurs Before 24 Weeks Gestation

- 1.9. The co-leads have overall responsibility for the review and its outputs.
- 1.10. An advisory panel will be appointed to ensure that service users, service providers and the full range of stakeholders directly shape the recommendations.
- 1.11. The Department of Health and Social Care will support the co-leads to deliver their responsibilities by providing administrative, research and analytical support.
- 1.12. The review will report to the Secretary of State for Health and Social Care.

### Co-production

- 1.13. The review will be undertaken in consultation with the General Register Office.
- 1.14. The review should closely involve service users and service providers in all aspects of its work. It should:
  - · seek to understand existing practice across different local areas;
  - · engage widely with stakeholders; and
  - make recommendations that have broad support among service users, providers, relevant professionals, and organisations affected.
- 1.15. The review period should be used to air differences and find shared solutions.

### **Outputs**

1.16. The review will prepare a report that identifies priorities and makes detailed recommendations for improvement.

### Devolution

- 1.17. The review is commissioned by and will report to the Department of Health and Social Care in England. Recommendations will extend to England in relation to matters that are devolved in Wales (including health), and England and Wales in relation to non-devolved matters (including registration).
- 1.18. The review should engage with the Welsh Government and stakeholders in Wales, where appropriate, to consider interfaces with Welsh legislation and practice.

# Annex C. Early Pregnancy Assessment Units in England

Information accessed December 2022 – January 2023

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
Airedale NHS     Foundation Trust	Airedale General Hospital, Skipton Rd, Steeton, Keighley, BD20 6TD	Not found	6 - 16 weeks	Referrals are received to the unit from health professionals such as your GP, midwife or via the emergency department. You are not able to refer yourself directly to the unit but staff are available to provide advice if you experience any pain, bleeding or other problem with your pregnancy in the early stages. https://www.airedale-trust.nhs.uk/service/maternity/early-pregnancy-assessment-unit/
2. Ashford and St Peter's Hospitals NHS Foundation Trust	St Peter's Hospital, Guildford Street, Lyne, Chertsey, KT16 0PZ	Monday to Friday 0900- 1500	Up to 12 weeks	This is an emergency service for women referred by their GP or A&E healthcare professionals with pain and /or vaginal bleeding in early pregnancy. referrals are made from midwives, GPs, and other medical staff. Please note that this is not a walk-in service.  There is also a self-referral form. https://www.ashfordstpeters.nhs.uk/epu#:~:text=This%20unit%20is%20sit uated%20on,not%20a%20walk%2Din%20service
3. Barking, Havering and Redbridge University Hospitals NHS Trust	Queens Hospital, Rom Valley Way, Romford, RM7 0AG	8am to 8pm, seven days a week	Up to 12 weeks	Telephone number provided

Ş	Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
		Floor, North Tower, Whitechapel, E1 1FR			
	Barts Health NHS Trust	Whipps Cross University Hospital, Whipps Cross Road, Leytonstone London, E11 1NR	8am - 8pm, Mon to Fri and 8.30am - 1pm, Sat and Sun	Up to 18 weeks	If you would like to be seen in the Early Pregnancy Assessment Unit, your GP will need to refer you. They should ring and make an appointment https://www.bartshealth.nhs.uk/gynaecology
I .	Bedfordshire Hospitals NHS Foundation Trust	Bedford Hospital, Kempston Road, Bedford, MK42 9DJ	Mon to Fri, 08-13:00, emergency scans 2-3pm will be booked on the day as required.	Up to 16 weeks	Sees Pregnant Women with Pain and/or bleeding in early pregnancy, pregnant women with a previous Ectopic or molar pregnancy, and pregnant women who have experienced 3 consecutive miscarriages or require heparin injections early in the pregnancy. Referral Process, Via GP, A&E, Community Midwife, By calling the clinic and self-referring if you have been previously asked to do so by the clinic. https://www.bedfordshirehospitals.nhs.uk/our-services/early-pregnancy/
	Bedfordshire Hospitals NHS Foundation Trust	Luton and Dunstable University Hospital, Lewsey Road, Luton, LU4 0DZ	Mon to Fri 08.00 – 12.30 and 14.00 – 17:00. Open every Sat morning 08.30 – 12.30 by appointment only, no walkins.	Up to 20 weeks	Referral Process Via GP, A&E, By calling the clinic. https://www.bedfordshirehospitals.nhs.uk/our-services/early-pregnancy/
10.	Birmingham Women's and Children's NHS Foundation Trust	Birmingham Women's Hospital, Mindelsohn Way, Birmingham B15 2TG	Mon to Fri: 8.15am - 5.30pm Sat and Sun: 8.30am -	6 to 12 weeks	Patients should be referred to the service by their GP, Accident and Emergency departments or other health professionals. https://bwc.nhs.uk/early-pregnancy-assessment-epau-and-acutegynaecology-serv
	Blackpool Teaching Hospitals NHS Foundation Trust	Victoria Hospital, Whinney Heys Road, Blackpool, FY3 8NR	Mon - Fri 8:30 - 17:00 (last scan at 16:30. Sat - closed. Sun 9:00-13:00 (emergency inpatients take priority)	6 - 16 weeks	We operate an appointment only system. All referrals will be triaged by clinical staff and patients will be provided with specialist care https://www.bfwh.nhs.uk/our-services/maternity/early-pregnancy/

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
12. Bolton NHS Foundation Trust	Royal Bolton Hospital, Minerva Road, Farnworth, BL4 0JR	24 hours – 7 days a week.	Up to 16 weeks	Contact our dedicated Early Pregnancy Telephone Triage Service. The nurse will assess your problem and where appropriate will advise for you to either be seen immediately in the Emergency Department or arrange for you to attend to be seen and assessed in our Early Pregnancy Assessment Unit. If you are unable to access the service, particularly if you have severe pain or heavy bleeding, please attend A&E. Here you will still be triaged by a team of Nurse Practitioners and Doctors. https://www.boltonft.nhs.uk/services/gynaecology/
13. Bradford Teaching Hospitals NHS Trust	Bradford Royal Infirmary, Duckworth Ln, Bradford BD9 6RJ	Weekdays: 07:30 – 15:00 Weekends and Bank Holidays: 09:00 – 13:00	6 - 16 weeks	The unit does not take self-referrals or walk-ins. Exceptions are women with a history of previous ectopic pregnancy or previous tubal surgery including sterilisation who will have been advised to contact the unit in future pregnancies. GPs, A&E and other health services may refer to the unit by contacting the early pregnancy unit directly or via switchboard. Reviews are by appointment only. While we aim to see you at your appointment time there may be a delay if an emergency arises. https://www.bradfordhospitals.nhs.uk/epu/
14. Buckingham Healthcare NHS Trust	Stoke Mandeville Hospital, Mandeville Road, Aylesbury, HP21 8AL	0800–1700 Monday–Friday	Up to 13 weeks	Telephone number provided https://www.buckshealthcare.nhs.uk/wp-content/Uploads/2021/05/Bleeding-in-early-pregnancy-V2-rvw-08-2022-WZZ1819.pdf
15. Buckingham Healthcare NHS Trust	Wycombe Hospital, Queen Alexandra Road, High Wycombe, HP11 2TT	0800–1300 Monday–Friday	Up to 13 weeks	Telephone number provided https://www.buckshealthcare.nhs.uk/wp-content/Uploads/2021/05/Bleeding-in-early-pregnancy-V2-rvw-08-2022-WZZ1819.pdf
<ol> <li>Calderdale and Huddersfield NHS Foundation Trust</li> </ol>	Calderdale Royal Hospital, Salterhebble, Halifax, HX3 0PW	Sun - Sat	Up to 16 weeks	Telephone number provided https://www.cht.nhs.uk/services/clinical-services/gynaecology

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rust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
17. Cambridge University Hospitals NHS Foundation Trust	The Rosie Hospital, Clinic 24, Robinson Way, Cambridge CB2 0QQ	Monday - Friday 08 – 20:00 (last patient accepted 19:15) and Saturday – Sunday 08:30 – 14:00 (last patient accepted 13:15). We are closed in Bank holidays.	Up to 13 weeks	Clinic 24 operates a telephone triage and referral system. If you have an early pregnancy or gynaecology concern, please contact Clinic 24 by telephone. Your call will be taken by an appropriately trained member of staff. You may be asked to attend Clinic 24, the Emergency Department or your GP. You may be given advice and informed that attendance is not currently necessary. Alternatively, you may be directly referred to Clinic 24 from your GP, the Emergency Department or your midwife. When Clinic 24 is closed, an out-of-hours telephone triage service is delivered by the staff of Daphne Ward, the in-patient gynaecology ward. If your concern does not require emergency care, we advise that you contact Daphne Ward rather than directly attending the Emergency Department. https://www.cuh.nhs.uk/clinics/early-pregnancy-clinic-24/
18. Chelsea & Westminster Westminster Hospital Foundation Trust	Chelsea and Westminster Hospital, 369 Fulham Road, London, SW10 9NH	Mon-Fri, 9am- 5pm. Sat morning diagnostic clinic is for early pregnancy complications —access to this clinic is only possible by attendance to our A&E during the preceding 24 hours.	Up to 20 weeks	We operate an appointment-only system, which means women should be referred by a healthcare professional (such as their GP or a doctor in the Emergency Department). The only exception to this is a history of previous ectopic pregnancy, when women can self-refer. Women who require urgent medical assistance in early pregnancy should go to the Emergency Department for review by the on-call gynaecology team. https://www.chelwest.nhs.uk/services/womens-health-services/early-pregnancy-assessment-unit-epau.
19. Chelsea & Westminster Westminster Hospital Foundation Trust	West Middlesex University Hospital, Twickenham Road, Isleworth, TW7 6AF	Mon–Fri, 9am– 5pm	Up to 18 weeks	We operate an appointment-only system, which means women should be referred by a healthcare professional (such as their GP or a doctor in the Emergency Department). The only exception to this is a history of previous ectopic pregnancy when women can self-refer. Women who require urgent medical assistance in early pregnancy should go to the Emergency Department for review by the on-call gynaecology team. https://www.chelwest.nhs.uk/services/womens-health-services/early-pregnancy-assessment-unit-epau

Ě	Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
20.	. Chesterfield Royal Hospital NHS Foundation Trust	Chesterfield Royal Hospital, Calow, Chesterfield, Derbyshire, S44 5BL	Mon - Fri	from 7 weeks pregnant, although this can be earlier, if deemed medically necessary.	This is an out-patient clinic and you may be referred for an appointment by your GP, Community Midwife, Out of hours GP or via our Emergency Department. Depending on your symptoms, your GP or other healthcare provider, may feel that you need to be seen more urgently. https://www.chesterfieldroyal.nhs.uk/our-services/early-pregnancy-problems#:~:text=We%20have%20a%20dedicated%20Early,or%20via%20our%20Emergency%20Department.
24.	Countess of Chester NHS Foundation Trust	Liverpool Rd, Chester CH2 1UL	Not found	Up to 16 weeks	Bleeding during pregnancy is relatively common and doesn't always mean there's a problem – but it can be a sign of complications. Call your midwife or General Practitioner (GP) immediately if you have any bleeding from your vagina. If the bleeding is heavy, please go to the Accident and Emergency (A&E) department. https://www.coch.nhs.uk/all-services/your-pregnancy/early-pregnancy.aspx https://www.coch.nhs.uk/all-services/gynaecology.aspx
22.	County Durham and Darlington NHS Foundation Trust	Bishop Auckland Hospital, Cockton Hill Rd, Bishop Auckland DL14 6AD	Mon - Weds	6 - 14 weeks	You must be referred by a health care professional e.g. GP/midwife. If you have had a previous ectopic pregnancy or 2 consecutive miscarriages, with the same partner, you can refer yourself. https://www.cddf.nhs.uk/our-services/division-of-women,-children-and-sexual-health/gynaecology/early-pregnancy-assessment.aspx
23.	County Durham and Darlington NHS Foundation Trust	Darlington Memorial Hospital, Hollyhurst Road, Darlington, County Durham, DL3 6HX	Mon - Fri	6 - 14 weeks	You must be referred by a health care professional e.g. GP/midwife. If you have had a previous ectopic pregnancy or 2 consecutive miscarriages, with the same partner, you can refer yourself. https://www.cddfi.nhs.uk/our-services/division-of-women,-children-and-sexual-health/gynaecology/early-pregnancy-assessment.aspx
24.	County Durham and Darlington NHS Foundation Trust	University Hospital of North Durham, North Road, Durham, County Durham, DH1 5TW	Mon - Fri	6 - 14 weeks	You must be referred by a health care professional e.g. GP/midwife. If you have had a previous ectopic pregnancy or 2 consecutive miscarriages, with the same partner, you can refer yourself. https://www.cddf.nhs.uk/our-services/division-of-women,-children-and-sexual-health/gynaecology/early-pregnancy-assessment.aspx
25.	Croydon Health Services NHS Trust	Croydon University Hospital, London Road, Croydon, CR77YE	Telephone triage Mon - Fri, 9:00 - 13:00. Scan Clinic Mon - Fri, 9:00 - 12:40	Up to 16 weeks	Telephone number provided https://www.croydonhealthservices.nhs.uk/a-to-z-of-services/service/early- pregnancy-unit-208/

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
26. Dartford and Gravesham NHS Trust	Darent Valley Hospital, Darent Wood Road, Dartford, DA2 8DA	8:00 - 18:00, 7 days a week, (Closed Christmas and New Year's Day)	5 - 16 weeks	EPU is a referral only service and patients must be referred by their GP/Midwife or through attendance to A&E. Patients will then be contacted via telephone by the EPU in order that an appointment can be booked. https://www.dgt.nhs.uk/services/a-z-services/early-pregnancy-unit
27. Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust	Bassetlaw Hospital, Kilton Hill, Worksop S81 0BD	Mon - Fri, 8.00am – 2.00pm	Up to 16 weeks	The Early Pregnancy Assessment Unit (EPAU) is a nurse led service and deals with non-urgent problems less than 16 weeks of pregnancy. An appointment system is in operation. Women can be referred either by a Community Midwife or GP, or they can contact the unit for advice themselves. It is important that women who use this service have had a positive pregnancy test. Depending on the urgency of the problem women will either be seen on the same day or given an appointment for the next working day or referred directly to the Gynaecology ward. https://www.dbth.nhs.uk/services/maternity/general-information/our-wards/
28. Doncaster and Bassetlaw Teaching Hospitals NHS Foundation Trust	Doncaster Royal Infirmary, Armthorpe Road, Doncaster, DN2 5LT	Mon - Fri, 8.00am to 5.00pm	Up to 16 weeks	The Early Pregnancy Assessment Unit (EPAU) is a nurse led service and deals with non-urgent problems less than 16 weeks of pregnancy. An appointment system is in operation. Women can be referred either by a Community Midwife or GP, or they can contact the unit for advice themselves. It is important that women who use this service have had a positive pregnancy test. Depending on the urgency of the problem women will either be seen on the same day or given an appointment for the next working day or referred directly to the Gynaecology ward.
29. East and North Hertfordshire NHS Trust	Lister Hospital, Corey's Mill Lane, Stevenage, SG1 4AB	08.30am – 7.00pm, Mon – Fri, 9.00am – 4.00pm, Sat, Sun and Bank Holiday (except	Not found	We accept GP, midwife and A&E referrals for assessment https://www.enherts-tr.nhs.uk/services/gynaecology/early-pregnancy-and-gynaecology-emergency-unit-epu/
30. East Cheshire NHS Trust	Macclesfield District General Hospital, Victoria Road, Macclesfield, SK10 3BL	Monday – Friday between 8.15 am and 11.00 am.	Up to 14 weeks	Women over 14 weeks gestation who develop a clinical symptom should be referred for an emergency antenatal clinic appointment or for emergency care. Referrals are received via GPs and midwives following set criteria. <a href="https://services.eastcheshire.nhs.uk/early-pregnancy-assessment-unit-epau">https://services.eastcheshire.nhs.uk/early-pregnancy-assessment-unit-epau</a>

Other Information	Not found https://www.ekhuft.nhs.uk/patients-and-visitors/information-for-patients/contact-us/contacting-a-ward-or-department/?entryid78=527649&p=5	Not found https://www.ekhuft.nhs.uk/patients-and-visitors/william-harvey-hospital/wards-and-departments/?entryid78=527647&p=2	If you are over 20 weeks of pregnancy please contact Maternity Triage. The Early Pregnancy Unit is classified as an Emergency Service and you may be invited to attend the unit for an appointment. Women are seen in order of clinical priority, which means that you may be in the department for longer than anticipated. You must telephone the unit before attending we do not run a walk-in clinic or service. https://elht.nhs.uk/services/maternity-and-newborn-services/early-pregnancy-assessment-unit	If you are experiencing bleeding, contact one of the following: your GP, your community midwife, out of hours service. If the bleeding is very heavy or you cannot manage your pain, please attend the Emergency Department (A&E). https://www.esneft.nhs.uk/service/bleeding-in-early-pregnancy/	Appointment only https://www.esht.nhs.uk/service/maternity/your-pregnancy/early-pregnancy-assessment-clinic/	Appointment only <a href="https://www.esht.nhs.uk/service/maternity/your-pregnancy/early-pregnancy-assessment-clinic/">https://www.esht.nhs.uk/service/maternity/your-pregnancy/early-pregnancy-assessment-clinic/</a>	Appointment only https://www.epsom-sthelier.nhs.uk/early-pregnancy	Appointment only https://www.epsom-sthelier.nhs.uk/early-pregnancy
Gestation	Not found	Not found	5 - 20 weeks	Not found	Up to 14 weeks	Up to 14 weeks	Up to 20 weeks	Up to 20 weeks
Opening times	Not found	Not found	Mon - Fri, 8:30 - 17:30	Monday - Friday, 8:00 - 16:00	Monday - Friday, 8:00 - 16:00	Monday to Friday, scan appointments 8:00am - 9:45am	Monday to Friday, 1.20pm to 3.20pm	Monday to Friday, 9am -12 noon
Hospitals providing Early Pregnancy Services	Queen Elizabeth Queen Mother Hospital, St. Peter's Road, Birchington Ward, Margate, CT9	William Harvey Hospital	Burnley General Teaching Hospital, Casterton Ave, Burnley BB10 2PQ	Ipswich Hospital NHS Trust, Heath Road, Ipswich, Suffolk IP4 5PD	Conquest Hospital, The Ridge, St. Leonards on Sea, TN37 7RD	Eastbourne District General Hospital, Kings Dr, Eastbourne BN21 2UD	Epsom General Hospital, Dorking Road, Epsom, KT18 7EG	St Helier Hospital, Wrythe Lane, Carshalton, SM5 1AA
Trust	31. East Kent Hospitals University NHS Foundation Trust	32. East Kent Hospitals University NHS Foundation Trust	33. East Lancashire Hospitals NHS Trust	34. East Suffolk and North Essex NHS Foundation Trust	35. East Sussex Healthcare	36. East Sussex Healthcare	37. Epsom and St Helier University Hospitals NHS Trust	38. Epsom and St Helier University Hospitals NHS Trust

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
39. Frimely Health NHS Foundation Trust	Frimely Park Hospital, Portsmouth Rd, Frimley, Camberley, GU16 7UJ	Not found	Up to 16 weeks	As this is an emergency service for women, it works as an extension to the Emergency Department. We accept referrals of early pregnancy patients with pain and bleeding from GP, midwife, emergency department and NHS 111 services. We sometimes accept self-referrals from patients if they have difficult accessing their GP surgery due to Covid restrictions. You can self-refer if you have a history of previous confirmed ectopic pregnancies, molar pregnancy, recurrent miscarriage (3 consecutive early pregnancy losses)  https://www.fhft.nhs.uk/services/epu-and-ugcc/#:~:text=The%20Early%20Pregnancy%20Unit%20is,early%20stages %20of%20your%20pregnancy.
40. Frimely Health NHS Foundation Trust	Wexham Park Hospital, Wexham Street, Slough, SL2 4HL	Not found	Up to 16 weeks	As this is an emergency service for women, it works as an extension to the Emergency Department. We accept referrals of early pregnancy patients with pain and bleeding from GP, midwife, emergency department and NHS 111 services. We sometimes accept self-referrals from patients if they have difficult accessing their GP surgery due to Covid restrictions. You can self-refer if you have a history of previous confirmed ectopic pregnancies, molar pregnancy, recurrent miscarriage (3 consecutive early pregnancy losses)  https://www.fhft.nhs.uk/services/epu-and-ugcc/#:~:text=The%20Early%20Pregnancy%20Unit%20is,early%20stages %20of%20your%20pregnancy.
41. George Eliot Hospital NHS Trust	George Eliot Hospital, College Street, Nuneaton, CV107DJ	Mon - Fri, 8:30 - 13:00	Up to 16 weeks	Telephone number provided https://www.geh.nhs.uk/directory-of-services/specialties-and-services/m/maternity/during-your-pregnancy/early-pregnancy-advice/
42. Gloucestershire Hospitals NHS Foundation Trust	Gloucestershire Royal Hospital, Great Western Road, The Woman's Centre, Gloucester, GL1 3NN	Monday to Friday from 8.30am to 4pm, and weekends and bank holidays 8.30am to	7 - 15 weeks	Referrals are usually made by your GP, midwife or healthcare professional. However, you can self-refer if you have previously had an ectopic or molar pregnancy. We do not offer a drop in service but aim to offer appointments within 48 hours of referral.  https://www.gloshospitals.nhs.uk/our-services/services-we-offer/gynaecology/early-pregnancy-assessment/

Trust	Hospitals providing Early Pregnancy	Opening times	Gestation	Other Information
43. Great Western Hospitals NHS Foundation Trust	Great Western Hospital, Marlborough Road, Floor 2, Swindon, SN3 6BB	The Unit is open at all times. Scans usually in the morning	Not found	The Unit supports women who are having complications in early pregnancy and/or arrive at hospital with emergency gynaecological problems. We scan for problems in early pregnancy - usually during the morning and on an appointment basis. Patients are treated according to medical need, not in the order in which they arrive. The Unit does not accept self-referrals, but you may be asked to attend the unit after seeing a healthcare practitioner.  https://www.gwh.nhs.uk/wards-and-services/early-pregnancy-unit-emergency-qynaecology-unit-epu-egu/
44. Guy's & St Thomas NHS Foundation Trust	St Thomas' Hospital, Lambeth Palace Road, 8th Floor North Wing, London, SE17EH	Mon - Fri, 8.30am to 6pm, Weekend and bank holidays, 9.30am to 3pm, Closed Christmas day	Up to 18 weeks	If you need urgent help when the unit is closed, please go to the emergency department. https://www.guysandstthomas.nhs.uk/our-services/early-pregnancy-andgynaecology-unit
45. Hampshire Hospitals NHS Foundation Trust	Basingstoke and North Hampshire Hospital Aldermaston Road, Basingstoke, Hampshire, RG24 9NA	Not found	Not found	Appointments are arranged via a referral from a GP or health worker. Women who have previously had an ectopic, molar pregnancy or whose last 2 pregnancies have ended in miscarriage can self-refer to the unit. https://hampshirehospitals.nhs.uk/our-services/az-departments-and-specialties/womenshealth/early-pregnancy-assessment-unit-epau
46. Hampshire Hospitals NHS Foundation Trust	Royal Hampshire County Hospital, Romsey Rd, Winchester SO22 5DG	Not found	Not found	Appointments are arranged via a referral from a GP or health worker. Women who have previously had an ectopic, molar pregnancy or whose last 2 pregnancies have ended in miscarriage can self-refer to the unit. https://hampshirehospitals.nhs.uk/our-services/az-departments-and-specialties/womenshealth/early-pregnancy-assessment-unit-epau
47. Harrogate and District NHS Foundation Trust	Harrogate District Hospital, Lancaster Park Road, Harrogate, HG2 7SX	08.30-14.30 Mon-Fri. Scans are performed between 9- 10.30am.	6 - 12 weeks	We accept referrals from healthcare professionals only. Self-referrals are only accepted from those with a history of recurrent miscarriage, previous ectopic or previous molar pregnancy.  https://www.hdft.nhs.uk/services/maternity-services/early-pregnancy-assessment/

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
48. Homerton Healthcare NHS Foundation Trust	Homerton University Hospital, Homerton Row, Hackney E96SR	Mon - Fri, 8:00 - 18:00 Sat 10:00 - 14:00	Up to 18 weeks	EPAU is a specialist unit that manages early pregnancy problems such as vaginal bleeding and abdominal pain. We see women in the first 18 weeks of pregnancy only. After 18 weeks, the patient is seen in the Emergency Obstetric Unit or Delivery Suite. Appointments can be made by GPs, ED (fast track) or other health professionals by telephoning the receptionist or via the online form on C&H CCG website. Self-referrals are accepted however, due to the current situation we are only accepting emergency referrals. https://www.homerton.nhs.uk/epau/
49. Hull University Teaching Hospitals NHS Trust	Hull Royal Infirmary, Women and Children's Hospital, Anlaby Rd, Hull HU3 2JZ	Monday to Friday – 7.45am to 5.45pm Saturday and Sunday – 7.30am to	6 - 15 weeks	Appointments can be made by GPs, A&E (fast track) or other health professionals. Self-referrals are accepted from women who have been diagnosed with recurrent miscarriage and seen by a Doctor within the Gynaecology Service.  Service. https://www.hey.nhs.uk/gynaecology/epau/
50. Imperial College Healthcare NHS Trust	Queen Charlotte's & Chelsea Hospital, Du Cane Road, London, W120HS	09.00 to 16.30, Monday to Friday	Not found	We offer emergency clinics that accept referrals from GPs, antenatal clinics, the main ultrasound department, urgent care centres at both sites and A&E at St Mary's Hospital. You can usually be seen on the same day as referral, or if non-urgent within two or three days.  https://www.imperial.nhs.uk/our-services/gynaecology/early-pregnancy-and-acute-gynaecology-units
51. Imperial College Healthcare NHS Trust	St Mary's Hospital, Praed Street, London, W21NY	09.00 to 16.30, Monday to Friday	Not found	We offer emergency clinics that accept referrals from GPs, antenatal clinics, the main ultrasound department, urgent care centres at both sites and A&E at St Mary's Hospital. You can usually be seen on the same day as referral, or if non-urgent within two or three days. https://www.imperial.nhs.uk/our-services/gynaecology/early-pregnancy-and-acute-gynaecology-units
52. Isle of Wight NHS Trust	St. Mary's Hospital, Parkhurst Road, Newport, Isle of Wight, PO30 5TG	Not found	6 - 12 weeks	Appointments are made via GPs, A&E or community midwives. We do not offer a walk in service at this time. https://www.iow.nhs.uk/our-services/planned-careservices/gynaecology/early-pregnancy-unit.htm
53. James Paget University Hospitals NHS Foundation Trust	James Paget University Hospital Foundation Trust, Gorleston, Norfolk, Great Yarmouth NR31 6LA	9:00 – 16:30 Monday to Friday.	6 to 12 weeks	Patients can be referred by their General Practitioner or Midwife. Patients are also referred by the Accident and Emergency Department. Patients must meet the criteria of having a positive pregnancy test and a history of being at least 6 weeks before a referral can be accepted. https://www.jpaget.nhs.uk/departments-services/departments-services-a-/dgynaecology/early-pregnancy-assessment-unit/

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
54. Kettering General Hospital NHS Foundation Trust	Rothwell Rd, Kettering NN16 8UZ	Not found	Not found	Maple is a 13 bedded inpatient ward for women experiencing Gynaecological and or Early pregnancy complications. Women attend Maple ward following assessment by our Gynaecology Team either as an Emergency admission via A&E, Gynaecology Outpatients or Gynaecology same day emergency care unit or as a planned admission for elective surgery. There is mention of a Rockingham Assessment Unit open 9:00 - 4:30. https://www.kgh.nhs.uk/download.cfm?ver=4783
King's College Hospital NHS Foundation Trust	King's College Hospital, Suite 8, 3rd floor, Golden Jubilee Wing, Denmark Hill, SE59RS	Monday to Friday: 9am to 4.30pm Weekends and bank holidays: 9am to 12.30pm	Up to 16 weeks	This is an emergency service for early pregnancy patients only. We do not accept walk-in gynaecology emergencies; these should be referred to the on-call gynaecology registrar. GPs wishing to refer a patient should complete the Early Pregnancy Unit (EPU) referral form and hand it to the patient to bring with them. Women wishing to be referred to King's College Hospital, London should be asked to call the EPU helpline on 020 3299 7232 for a telephone assessment and to book an appointment. Women should bring their referral letter with them to their appointment. We also accept self-referrals via the EPU helpline.
King's College Hospital NHS Foundation Trust	Princess Royal University Hospital, Famborough Common, Orpington, BR6 8ND	9am to 12.30pm, Monday to Friday.	Not found	Urgent Early Pregnancy Unit referrals: Bromley GPs should use the Referrals Optimisation Tool to refer patients to these services. GPs from other boroughs, and other health professionals, should complete the Early Pregnancy Unit referral form and email it. https://pruh.kch.nhs.uk/services/gynaecology/
57. Kingston Hospital NHS Foundation Trust	Kingston Hospital, Galsworthy Road, Kingston-Upon- Thames, KT17QB	Not found	Not found	The Jasmine Unit is our emergency gynaecology and early pregnancy assessment unit. Referrals are done by GPs, Consultants, and Community Midwives. You can be referred to the unit by your GP or following a visit to our emergency (A&E) department. Patients with recurrent miscarriage (3 or more miscarriages in a row) or who have had a previous ectopic pregnancy and are now in the early stages of a new pregnancy can refer themselves for assessment by calling the unit. https://kingstonhospital.nhs.uk/department/early-pregnancy-and-acutegynaecology-unit-jasmine-unit/
58. Lancashire Teaching Hospital NHS Foundation Trust	Royal Preston Hospital, Sharoe Green Lane, Fulwood, PR2 9HT	Not found	Not found	The consultants are supported by a team of specialist nurses in urogynecology, colposcopy, sub-fertility, early pregnancy disorders, perioperative management that support patients through their care https://www.lancsteachinghospitals.nhs.uk/our-services?service=30

Up to 16 weeks	Not found Up t

Ĕ	Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
. 19	. Liverpool Women's NHS Foundation Trust	Liverpool Women's Hospital, Crown Street, Liverpool, L8 7SS	8am – 4pm on weekdays	6 - 12 weeks	Assessment is by appointment ONLY. We aim to offer an ultrasound scan within 72 hours of referral. Access is via: Self-referral by telephone assessment, Clinical assessment in the Emergency Department <a href="https://www.liverpoolwomens.nhs.uk/our-services/gynaecology/early-pregnancy-assessment-unit/">https://www.liverpoolwomens.nhs.uk/our-services/gynaecology/early-pregnancy-assessment-unit/</a>
62.	London North West University Healthcare NHS Trust	Ealing Hospital, Uxbridge Road, Southall, UB13HW	Working Hours	Up to 13 weeks	We accept referrals from: GPs, Emergency Departments, Urgent care centres, local family planning clinics, pregnant women (self-referrals). Outside working hours, we accept referrals from our Emergency Department reception. https://www.lnwh.nhs.uk/other-referral-pathways/early-pregnancy-unit-epu-referrals-1162/
63.	. London North West University Healthcare NHS Trust	Northwick Park Hospital, Watford Road, Lister Unit, Level 4, Harrow, HA13UJ	Not found	Up to 20 weeks	We accept referrals from: GPs, Marie Stope clinic, Emergency Departments, Urgent Care Centres (UCC), Antenatal Clinic (ANC). our on-call gynaecology team. Please note that our clinic at Northwick Park is not a walk-in service and therefore we cannot accept self-referrals. https://www.lnwh.nhs.uk/other-referral-pathways/early-pregnancy-unit-epu-referrals-1162/
	. Maidstone and Tunbridge Wells NHS Trust	Tunbridge Wells Hospital, Tunbridge Road, Tunbridge Wells, TN2 4QJ	Monday to Friday 8am - 8pm	Up to 16 weeks	We have a dedicated Early Pregnancy and Emergency Gynaecology Service which operates Monday to Friday 8am -8pm. Referral is through your GP or other professional who deems this the correct pathway for your treatment. If you are experiencing problems when there is no access to your GP, you will need to attend the Accident & Emergency department. The Early Pregnancy Clinic at Tunbridge Wells Hospital runs to timed appointments. These appointments can be made by your GP, Midwife or the Emergency Department. Sometimes emergency patients need to be seen and you may have to wait for your scan or doctors review. We will advise of any waiting times on the day.  https://www.mtw.nhs.uk/service/gynaecology/#:~:text=We%20have%20a %20dedicated%20Early,correct%20pathway%20for%20your%20treatmen t.
65.	. Manchester University NHS Foundation Trust	Wythenshawe Hospital, Emergency Gynaecology Unit, F16 - Southmoor Road, Wythenshawe, Greater Manchester M23 9LT	This is a 24 hour walk in service. Women are advised to call first.	Up to 16 weeks	We are classified as an Accident and Emergency (A&E) service. Patients are seen in order of clinical priority, which means that you may be in the department for longer than anticipated.  https://mft.nhs.uk/saint-marys/services/gynaecology/emergency-gynaecology/

Other Information	Ultrasound appointments are by referral only. Referrals can be made by your GP or out of hours GP, midwife or the Emergency Department (ED). Positive urine pregnant test and Up to 12 weeks pregnant with: Abdominal pain, Vaginal bleeding, 2 or more previous miscarriages, Previous ectopic pregnancy, Previous tubal surgery, Intrauterine device (coil) in situ, Persistent vaginal bleeding after surgical management of miscarriage. There are no walk-in slots or self-referrals. If you are over 14 weeks, you must contact the Maternity Department for advice. If you have any of the above problems are you are between 12 and 14 weeks pregnant, you will need a referral to the Gynaecology Emergency Clinic or for urgent medical assistance, go to the Emergency Department. https://www.medway.nhs.uk/services/early-pregnancy-assessment-clinic.htm	This is not a walk-in service, appointments only via GP, Emergency Department, or another health professional. The team in EPAU assess the referral and then contact patients by telephone within a few days for a telephone consultation or if necessary, to arrange an appointment. https://www.mse.nhs.uk/epau/#:~:text=The%20EPAU%20is%20a%20specialist, weeks%20at%20Basildon%20University%20Hospital).	This is not a walk-in service, appointments only via GP, Emergency Department or another health professional. The team in EPAU assess the referral and then contact patients by telephone within a few days for a telephone consultation or if necessary, to arrange an appointment. https://www.mse.nhs.uk/epau/#:~:text=The%20EPAU%20is%20a%20spe cialist, weeks%20at%20Basildon%20University%20Hospital).	This is not a walk-in service, appointments only via GP, Emergency Department or another health professional. The team in EPAU assess the referral and then contact patients by telephone within a few days for a telephone consultation or if necessary, to arrange an appointment. https://www.mse.nhs.uk/epau/#:~:text=The%20EPAU%20is%20a%20specialist, weeks%20at%20Basildon%20University%20Hospital).	You can be referred to EPAU by: GP or Practice Nurse, Midwives, Emergency Department, Consultants (hospital Doctors), Antenatal Clinic, Inpatient Ward referral https://www.mcht.nhs.uk/our-services/gynaecology/early-pregnancy-assessment-unit
Gestation	Up to 12 weeks	Up to 14 weeks	Up to 17 weeks	Up to 17 weeks	Up to 16 weeks
Opening times	Monday to Friday: 9am to 4.30pm	09.00-17.00 Monday to Friday	09.00-17.00 Monday to Friday	08.00-16.00 Monday to Friday	Mon to Fri, 08:00 to 16:00 with ultrasound scanning facilities from 09:00 to 12:00, excluding bank holidays.
Hospitals providing Early Pregnancy Services	Medway Maritime Hospital, Windmill Rd, Gillingham, ME7 5NY	Basildon University Hospital, Nethermayne, Basildon, Essex SS16 5NL	Broomfield Hospital, Court Rd, Broomfield, Chelmsford CM1 7ET	Southend University Hospital, Prittlewell Chase, Westcliff on Sea, Essex, SS0 0RY	Leighton Hospital, Middlewich Road, Crewe. CW1 4QJ
Trust	66. Medway NHS Foundation Trust	67. Mid and South Essex NHS Foundation Trust	68. Mid and South Essex NHS Foundation Trust	69. Mid and South Essex NHS Foundation Trust	70. Mid-Cheshire Hospitals NHS Foundation Trust

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
71. Milton Keynes University Hospital	Milton Keynes General Hospital Foundation Trust, Eaglestone, Bletchley, MK65LD	Not found	Within the first 20 weeks of pregnancy	Your GP or Midwife will phone the nurse-led unit and book an appointment for you.  https://www.mkuh.nhs.uk/patient-information-leaflet/the-early-pregnancy-assessment-unit-epau
72. Norfolk and Norwich University Hospitals NHS Foundation Trust	Norfolk & Norwich University Hospital, Colney Lane, Norwich, NR4 7UY	Not found	6 - 16 weeks	A Doctor, Nurse or Midwife will have arranged an appointment for you. Early-Pregnancy-Assessment-UnitEPAUV4.pdf
73. North Bristol NHS Trust	Southmead Hospital, Southmead Road, Cotswold Centre, Bristol BS10 5NB	8.30am and 11am Monday to Friday. Scanning starts at 9am.	6 - 18 weeks	The Early Pregnancy Assessment Clinic (EPAC) is an emergency service available to all women referred by their GP or Health Professional. https://www.nbt.nhs.uk/our-services/a-z-services/gynaecology/early-pregnancy-assessment-clinics-epac
74. North Cumbria Integrated Care NHS Foundation Trust	Cumberland Infirmary, Newtown Road, Carlisle CA2 7HY	Not found	Not found	This hospital has maternity and gyneacology services but there is no mention of EPAU services https://pregnancyandbirthchoices.co.uk/unit/the-cumberland-infirmary/
75. North Cumbria Integrated Care NHS Foundation Trust	West Cumberland Hospital, Homewood Road, Hensingham, Whitehaven CA28 8JG	Not found	Not found	This hospital has maternity and gyneacology services but there is no mention of EPAU services https://pregnancyandbirthchoices.co.uk/unit/west-cumberland-hospital/
76. North Middlesex University Hospital NHS Trust	North Middlesex University Hospital, Sterling Way, London, N181QX	Not found	Up to 18 weeks	About our women's ambulatory day unit (WADU). We are a service for acute gynaecological and early pregnancy problems. We look after women Up to 18 weeks of pregnancy for a variety of problems in a specially designed emergency area, including clinic rooms, scan facilities and treatment areas. Conditions we treat: Early pregnancy complications, including bleeding and pain, Acute vulval and vaginal problems, Acute pelvic pain. Please note, we are not a walk-in service. If you are visiting us for an emergency, you will normally have been via our A&E or referred from your GP. We are not appointment based, so you may have to wait if our service is busy. Appointments for scans: We are able to offer same day treatment for lots of women that visit us.
77. North Tees and Hartlepool NHS Foundation Trust	University Hospital of Hartlepool, Holdforth Road, Hartlepool, TS24 9AH	Monday to Friday between 8am and 4pm	Under 18 weeks	You will be referred to us by your GP, midwife, accident and emergency department or One Life Hartlepool if you have problems during early pregnancy such as pain or bleeding or have had a previous ectopic pregnancy or a history of miscarriage. We don't accept self-referrals. https://www.nth.nhs.uk/services/early-pregnancy-assessment-clinic/

Trust	ıst	Hospitals providing Early Pregnancy	Opening times	Gestation	Other Information
78.	North Tees and Hartlepool NHS Foundation Trust	University Hospital of North Tees, Hardwick Road, Stockton-on- Tees. TS19 8PE	Monday to Friday between 8am and 4pm	Under 18 weeks	You will be referred to us by your GP, midwife, accident and emergency department or One Life Hartlepool if you have problems during early pregnancy such as pain or bleeding or have had a previous ectopic pregnancy or a history of miscarriage. We don't accept self-referrals. https://www.nth.nhs.uk/services/early-pregnancy-assessment-clinic/
79.	North West Anglia NHS Foundation Trust	Peterborough City Hospital, Bretton Gate, Peterborough, PE2 3	Mon - Fri, 8:00 - 18:00 Sat & Sun, 8:00 - 12:00	Up to 16 weeks	The unit is run by senior specialist nurses and doctors. https://www.nwangliaft.nhs.uk/maternity/im-pregnant/concerns-during- pregnancy-who-to-call/
80.	. Northampton General Hospital NHS Trust	Northampton General Hospital, Cliftonville, Northampton NN1 5BD	Our service currently runs between Sunday and Friday.	Up to 20 weeks	If you are experiencing severe pain or very heavy bleeding in early pregnancy (less than 20 weeks) you should dial 999 or attend accident and emergency immediately. Our emergency department colleagues have 24-hour access to our gynaecology emergency on call team. You should call your midwife or GP immediately if you have any bleeding from your vagina. You can contact us and book an appointment. Out of hours advise can be obtained by calling our gynaecology emergency assessment unit nurse. Your GP can also request a clinical appointment for you. https://www.northamptongeneral.nhs.uk/Services/Our-Clinical-Services-and-Departments/Obstetrics-and-Gynaecology/Maternity/Early-Pregnancy-Service.aspx
81.	Northern Care Alliance NHS Foundation Trust	Royal Oldham Hospital, Rochdale Road, Oldham, OL1 2JH	Not found	Up to 16 weeks	Referrals into our services are taken from: GP, Community Midwife, Emergency Department (ED), Urgent Treatment Centre (UTC). There are no self-referral routes except for women suffering multiple miscarriages, who will be given the direct contact for the Early Pregnancy Specialist Nurses. https://www.northerncarealliance.nhs.uk/patient-information/maternity-services/gynaecology-services?q=%2Fpatient-information%2Fmaternity-services%2Fgynaecology-services
82.	. Northern Lincolnshire and Goole NHS Foundation Trust	Diana Princess of Wales Hospital, Scartho Road, Grimsby, DN332BA	Mon - Fri, 8:00 - 16:00	from 6 weeks Up to 20 weeks	It is an appointment-only system and referrals must come from a health professional. https://www.nlg.nhs.uk/services/maternity/assessment-centre/#:~:text=Early%20Pregnancy%20Assessment%20Unit%20Scunthorpe,19%20weeks%20and%206%20days.
83.	Northern Lincolnshire and Goole NHS Foundation Trust	Scunthorpe General Hospital, Cliff Gardens, Scunthorpe, North Lincolnshire, DN15 7BH	Mon - Fri, 8:00 - 20:00 Sat and Bank Holidays, 8:00 - 16:00	from 6 weeks Up to 20 weeks	It is an appointment-only system and referrals must come from a health professional. https://www.nlg.nhs.uk/services/maternity/assessment-centre/#:~:text=Early%20Pregnancy%20Assessment%20Unit%20Scunthorpe,19%20weeks%20and%206%20days.

Other Information	Many early pregnancy symptoms, like nausea, heartburn and fatigue are normal and nothing to worry about. However, if you have other symptoms such as vaginal bleeding, abdominal pain or hyperemesis (severe vomiting and nausea) you should contact your GP or midwife who will refer you to our Early Pregnancy Assessment Unit. https://www.nuh.nhs.uk/if-you-have-complications/	Referrals accepted from: GP / out of hours, A&E / Gynaecology ward, BPAS / sexual health, Midwives, Patients (self-referral). If patient is well and does not need immediate medical attention or admission: Give patient contact details for EPAU for patient to make self-referral. Advise patient to call the clinic. No letter from the GP or other healthcare provider is required. If seeing a patient outside of clinic hours, instruct patient to call clinic 8.00am - 10.00am the next morning to speak with a triage nurse who will arrange an appointment. This appointment may not always be the same day. For patients needing referral after 11.00am Saturday or on Sunday, advise patient to call on Monday morning 8.00am - 10.00am. Patients under sixteen weeks gestation with: threatened miscarriage, abdominal pain and positive pregnancy test previous ectopic pregnancy and a positive pregnancy test, have had no fetal heart heard by sonicaid >15/40, Patients with suspected ectopic pregnancy should be referred directly through the on-call gynaecology registrar as an emergency.  https://www.ouh.nhs.uk/services/referrals/womens/gynaecology/horton-epac.aspx	Women attending EPAU do not need to have been seen by a GP or have a referral letter. They do need to contact EPAU to make an appointment so that we can make sure they are being seen in the appropriate place. https://www.ouh.nhs.uk/services/referrals/womens/gynaecology/ugc-ir.aspx
Gestation	Not found	Up to 16 weeks	Not found
Opening times	Not found	Monday to Friday 8.00am - 6.00pm Saturday 9.00am - 12 noon	Mon to Fri 8.00am - 6.00pm Sat 9.00am - 2.00pm. Outside clinic hours we will see women on the Gynaecology Ward.
Hospitals providing Early Pregnancy Services	Queen's Medical Centre, Nottingham University Hospitals NHS Trust, Derby Road, Nottingham, NG7 2UH	Horton Hospital, Banbury, OX16 9AL	John Radcliffe Hospital, Headley Way, Women's Centre, Headington OX3 9DU
Trust	84. Nottingham University Hospitals NHS Trust	85. Oxford University Hospitals NHS Foundation Trust	86. Oxford University Hospitals NHS Foundation Trust

Other Information	The Early Pregnancy Assessment Unit (EPAU) is a community service which cares for women who are in the early stages of pregnancy and experiencing pain, bleeding or other problems relating to their pregnancy. If you are bleeding heavily (having to change your sanitary pad more than once an hour) or experiencing a lot of pain, please go straight to A&E at your nearest hospital. You must have an appointment before attending EPAU: it is important that we understand your concerns and ensure you receive the right care. Please contact us to arrange an appointment. If you are experiencing a problem your GP can refer you to EPAU, but you do not need to visit your GP before contacting the clinic. You do not need to have a letter from your GP or any other healthcare professional. https://www.ouh.nhs.uk/services/departments/gynaecology/epau/#contact	The unit accepts referrals from GP's, midwives, the antenatal clinic and via the Emergency Department https://www.porthosp.nhs.uk/departments-and-services/early-pregnancy-assessment-unit-epa/96925#pageLink4	Must be referred https://www.royalberkshire.nhs.uk/our-wards/early-pregnancy-unit-epu/	The early pregnancy unit is a specialist assessment and scanning service for women who are Up to 14 weeks pregnant and have experienced pain and / or vaginal bleeding. Although we are able to reassure most patients that their pregnancy is progressing normally, if we do find any problems, we are able to offer a full range of treatment options. We also look after women who have miscarried or have an ectopic pregnancy. We can often offer treatment using medicines as an outpatient instead of the patient having to come in for an operation. Your GP or midwife will be able to refer you (24 hr) by contacting the on-call gynaecology/https://www.royalcornwall.nhs.uk/services/gynaecology/	Referrals may only be made through your GP or midwife, the unit does not take self-referrals.  https://www.rdehospital.nhs.uk/services/gynaecology-female-reproductive-system/early-pregnancy-assessment-unit-epau/
Gestation	Not found	6 - 12 weeks	6 to 16 weeks	Up to 14 weeks	6 - 12 weeks
Opening times	Monday to Friday 8.00am - 6.00pm	Monday to Friday (excluding bank holidays), 8am to 4pm	8am - 6pm Mon - Fri excluding bank holidays	Not found	Not found
Hospitals providing Early Pregnancy Services	Rose Hill Community Centre Carole's Way Rose Hill Oxford OX4 4HF	Queen Alexandra Hospital, Southwick Hill Road, Portsmouth, PO6 3LY	Royal Berkshire Hospital, London Road, Reading, RG1 5AN	Royal Cornwall Hospital, 2 Penventinnie Ln, Truro TR1 3LQ	Royal Devon & Exeter Hospital, Barrack Road, Centre for Women's Health, Exeter, EX2 5DW
Trust	87. Oxford University Hospitals NHS Foundation Trust	88. Portsmouth Hospitals University NHS Trust	89. Royal Berkshire NHS Foundation Trust	90. Royal Cornwall Hospitals NHS Trust	91. Royal Devon & Exeter NHS Foundation Trust

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
92. Royal Devon University Healthcare NHS Foundation Trust	North Devon District Hospital, Raleigh Park, Petter Day Treatment Unit, Ladywell Unit, Barnstaple, EX31 4JB	Monday - Friday	Not found	You will need to be referred to us by your GP or midwife. 08.30 to 16.00 Monday to Friday contact the Petter Day Treatment Unit team to book patient into next available Emergency Pregnancy Assessment Clinic. Outside of these hours and days the Gynaecology SHO can be bleeped via the hospital switchboard. If a patient has a booked scan appointment and their condition is deteriorating they may contact the Petter Day Treatment Unit directly for advice and guidance. https://www.northdevonhealth.nhs.uk/2016/09/early-pregnancy-assessment-clinic/https://northeast.devonformularyguidance.nhs.uk/refer-cv19/maternity-and-early-pregnancy-services
93. Royal Free London NHS Foundation Trust	Barnet Hospital, Wellhouse Ln, Barnet EN5 3DJ	Monday to Friday, from 9am-5pm	Not found	Referrals are either from GP or the emergency department. Urgent GP referrals are seen on the same day. Non-urgent referrals seen on the same or next day.  https://www.royalfree.nhs.uk/services/services-a
94. Royal Free London NHS Foundation Trust	Royal Free Hospital, Pond St, London, NW3 2QG	Monday to Friday from 7.30am to 8pm with scanning facilities from 9am-5pm.	Not found	We do not currently provide a walk-in service. Referrals are either from a GP, the accident and emergency unit or the urgent care centre. We also take referrals from other health care providers in both the public and private sectors. Patients with three previous, recurrent miscarriages, a previous ectopic pregnancy or previous molar pregnancy can self-refer to the Royal Free Hospital by contacting unit prior to attendance on the telephone numbers above. Specialist nurses also provide advice by telephone during opening hours. Urgent GP referrals are seen on the same day. Non-urgent referrals seen on the same or next day. During working hours, women needing EPAGU services who attend A&E will be sent directly to the unit. Out of hours, they will either be given an appointment to attend the next day or will be seen by the on-call medical team. https://www.royalfree.nhs.uk/services/services-a-z/gynaecology/emergency-gynaecology/
95. Royal Surrey NHS Foundation Trust	Royal Surrey County Hospital, Egerton Road, Guildford, GU2 7XX	Not found	Up to 14 weeks	Early Pregnancy Unit (EPAU): The Early Pregnancy Unit is a referral only service for woman who experience problems or complications early in pregnancy.  https://www.royalsurrey.nhs.uk/discover-our-clinic-sites-and-ward-areas/

on Other Information	Up to 14 weeks  The EPAC is an open access clinic; patients do not need to be referred by a GP or midwife. All women who wish to attend the early Pregnancy Assessment Clinic (EPAC) must telephone in advance. This clinic is no longer a walk-in service. If you are more than 14 weeks pregnant you will need to contact your GP or midwife, who may refer you to the gynaecology emergency assessment clinic (GEAC)  https://www.ruh.nhs.uk/patients/services/gynaecology/early_pregnancy_a	Up to 12 weeks  Referral to EPU is via your GP, Midwife, Paramedic, ED or Private Ultrasound provider. Self-referral is only accepted for women based on their previous history of problems in early pregnancy, such as ectopic pregnancies or a molar pregnancies.
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Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
102. South Tees Hospitals NHS Foundation Trust	James Cook University Hospital, Marton Road, Middlesbrough TS4 3BW	Mon - Fri	Up to 12 weeks	The EPAU has ultra-sound scan facilities from Monday to Friday and can organise an ultra-sound scan for women within the unit as appropriate.  Early pregnancy assessment unit (EPAU) - South Tees Hospitals NHS  Foundation Trust
103.South Tyneside and Sunderland NHS Foundation Trust	South Tyneside District Hospital, Harton Ln, South Shields NE34 0PL	Mon: 2 - 5pm Tues: 9 - 5pm Wed: 2 - 5pm Thurs: 9 - 5pm Fri: 2 - 5pm	Not found	https://www.southtees.nhs.uk/services/maternity/maternity-wards-at- james-cook/early-pregnancy-assessment-unit/
104.South Tyneside and Sunderland NHS Foundation Trust	Sunderland Royal Hospital, Chester Lodge, Kayll Road, Tyne & Wear, SR4 7TP	Mon - Fri 8:30 am to 8:30 PM	7 - 14 weeks	If you have any vaginal bleeding in early pregnancy we are here to Support you. If this happens between 7 and 14 weeks, contact your GP or speak to your Community Midwife. They will arrange for a scan to check everything is ok. If this bleeding is heavy and you feel unwell, this could be more serious. You should go to your local Emergency Department as soon as possible. https://www.stsft.nhs.uk/services/maternity-new/antenatal
105.South Warwickshire University NHS Foundation Trust	Warwick Hospital, Lakin Road, Warwick CV34 5BW	7 days a week	Up to 20 weeks	If you have any concerns please contact your GP or Midwife in the first instance, they can then arrange an appointment for you. Self-referrals are not accepted. https://www.swft.nhs.uk/our-services/adult-hospital-services/gynaecology
106.Southport and Ormskirk Hospital NHS trust	Ormskirk District General Hospital, Dicconson Way, Wigan Road, Ormskirk, Lancashire, L39 2AZ	Not found	Not found	Our gynaecology assessment bay allows women to refer themselves directly if they have a gynaecological problem that requires immediate attention. We also have an early pregnancy assessment unit for women with complications such as bleeding in early pregnancy. https://www.southportandormskirk.nhs.uk/services/womens-health/
107.St George's University Hospitals NHS Foundation Trust	St George's Hospital, Blackshaw Road, Tooting, SW170QT	Mon -Fri, 08.30am- 11.00am Sat 08.30am- 11.00am – Emergencies only Sun and bank holidays –	Up to 14 weeks	This is a walk- in service meaning that you can self-refer and do not need to have seen a GP first. You must have a positive pregnancy test but be less than 14 weeks pregnant. Please note you may experience a wait of Up to four hours. When referred from the Emergency Department to come for 8.30am, please note that this is not an appointment, but the time at which the clinic opens. You will of course be assessed and triaged. https://www.stgeorges.nhs.uk/service/maternity-services/your-pregnancy/early-pregnancy/

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
108. <b>St Helen's and</b> Knowsley Teaching Hospitals NHS Trust	Whiston Hospital, Buchanan Suite, Warrington Road, Whiston L35 5DR	Mon to Fri - 09.00 to 17.00 hours, Sat- 09.00 to 12.30 Occasional bank holidays - contact clinic	Not found	This is an appointment only clinic for patients who are in early pregnancy. At this clinic you would be triaged over the telephone by a member of the BEP team, following this consultation you may be asked to attend the hospital for a scan or blood test. https://www.sthk.nhs.uk/our-services?service=90
109. Stockport NHS Foundation Trust	Stepping Hill Hospital, Poplar Grove, Women's & Children's Department, Stockport, SK2 7JE	Mon – Fri, 8.30am - 5pm (not weekends or public bank holidays) Sun, urgent cases only 8.00	6 - 16 weeks	We have an appointment system for early pregnancy problems and aim to provide care and on-going support. We will take self-referrals from patients who are between 6-16 weeks pregnant with existing or previous complications during pregnancy. To self-refer you may call us on the number provided, we will also accept referrals from doctors or midwives. https://www.stockport.nhs.uk/ServicesDetail.aspx?id=837
110.Surrey and Sussex Healthcare NHS Trust	East Surrey Hospital, Canada Avenue, Redhill, RH1 5RH	Monday- Friday 9am - 4pm	Up to 16 weeks	We have replaced our previous telephone advice line with an Online Portal to increase accessibility to our service, for more timely communication and assessment. When you submit an enquiry, the Triage nurse will review this within two hours of receipt (during unit open hours). Response times will vary and communication may be a reply email, or a phone call, depending on your enquiry. This may be a reply email, or a phone call, depending on your enquiry. If non-urgent, enquiries will be responded to within 1 working day of receipt. Can if you have had a previous Molar Pregnancy/ Ectopic pregnancy/ Recurrent Miscarriage as per National Guidance.  https://www.surreyandsussex.nhs.uk/our-services/womens-brites/maternity-services/early-pregnancy/early-pregnancy-unit
111. Tameside and Glossop Integrated Care NHS Foundation Trust	Tameside General Hospital, Fountain Street, Ashton under Lyne, OL6 9RW	Not found	Not found	https://tamesideandglossopicft.nhs.uk/services/gynaecology

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
117.The Princess Alexandra Hospital NHS Trust	Princess Alexandra Hospital, Hamstel Road Zone A - location A46, Harlow, CM20 1QX	Monday to Friday, 9am to 4pm and is closed on bank holidays.	Up to 22 weeks	To keep our patients safe, we are currently offering a telephone advice, triage and referral service. https://www.pah.nhs.uk/the-early-pregnancy-unit/
118.The Queen Elizabeth Hospital King's Lynn NHS Foundation Trust	Queen Elizabeth Hospital, Gayton Road, King's Lynn, Norfolk, PE30 4ET	Monday to Friday 8.00am – 5.30pm excluding Bank Holidays	Up to 16 weeks	The Early Pregnancy Unit operates a telephone triage and referral system. We are unable to accept self-referrals for symptomatic patients. http://www.gehkl.nhs.uk/Early-Pregnancy-Unit.asp?s=information&ss=departmental.information&p=early.pregnancy.unit
119.The Rotherham NHS Foundation Trust	Rotherham General Hospital, Moorgate Road, Rotherham, S60 2UD	Monday to Friday 8am until 4pm. (Please note, we are closed bank holidays).	Up to 20 weeks	You need to have an appointment to attend EPAU as unfortunately we cannot accept walk-ins. We do have a telephone line you can call to speak to one of our experienced nurses or midwives who will be able to assess your symptoms and provide you with advice. If you need to attend the unit, you will be offered an appointment for a face to face assessment. <a href="https://www.therotherhamft.nhs.uk/Maternity">https://www.therotherhamft.nhs.uk/Maternity</a> and Gynaecology/Early Pregnancy Assessment Unit/#:~:text=The%20Rotherham%20NHS%20Foun dation%20Trust,to%2019%2B6%20weeks%20gestation.
120.The Royal Wolverhampton Hospitals NHS Trust	New Cross Hospital Wolverhampton Road Wolverhampton WV10 0QP	Not found	Not found	This hospital has maternity and gyneacology services but there is no mention of EPAU services https://www.royalwolverhampton.nhs.uk/services/service-directory-a-z/gynecology-assessment-unit/
121.The Shrewsbury and Telford Hospital NHS Trust	Princess Royal Hospital, Apley Castle, Grainger Drive, Telford, TF1 6TF	Not found	Up to 16 weeks	Patients are referred for pain and bleeding and referrals are made by GP, midwife, Emergency Department or Gynaecology Emergency Assessment Area. Patients can also self-refer if they have been seen by EPAS in the current pregnancy, have had a previous ectopic pregnancy, or have had 3 recurrent miscarriages.  https://www.sath.nhs.uk/wards-services/az-services/maternity/early-pregnancy-assessment-service-epas/#:~:text=To%20contact%20the%20Gynaecological%20Unit,and%20 services%2C%20please%20click%20there.
122.The Shrewsbury and Telford Hospital NHS Trust	Royal Shrewsbury Hospital, Mytton Oak Road, Shrewsbury, SY3 8XQ	Not found	Up to 16 weeks	Patients are referred for pain and bleeding and referrals are made by GP, midwife, Emergency Department or Gynaecology Emergency Assessment Area. Patients can also self-refer if they have been seen by EPAS in the current pregnancy, have had a previous ectopic pregnancy, or have had 3 recurrent miscarriages.  https://www.sath.nhs.uk/wards-services/az-services/maternity/early-pregnancy-assessment-service-pregnancy-assessment-service-pregnancy-assessment-service-service-pregnancy-assessment-service-service-pregnancy-assessment-service-service-pregnancy-assessment-service-service-pregnancy-assessment-service-service-services/200nit, and%20

Trust	Hospitals providing Early Pregnancy	Opening times	Gestation	Other Information
123.Torbay and South Devon NHS Foundation Trust	Services Torbay Hospital, Lawes Bridge, Torquay, TQ2 7AA	Not found	Not found	Patients will usually be seen on the next working day. After a referral by their GP we ask GPs to carry out the following tests: a quantitative HCG blood test; and blood group check. All gynaecology and early pregnancy (less than 24 weeks) emergencies will be dealt with round-the-clock through the Emergency Assessment Unit (EAU) on the Torbay site – by GP or self-referral.
124.United Lincolnshire Hospitals NHS Trust	Lincoln County Hospital, Greetwell Road, Lincoln, LN25QY	Not found	Under 20 weeks	Early pregnancy assessment is for women under 20 weeks pregnant. This service can be accessed for pain or bleeding in early pregnancy via your GP. GP's leave a message on the early pregnancy answer phone and then you will be contacted by a member of the nursing staff with an appointment for scan and assessment. We aim to provide an appointment within 48 hours however, this is not always possible. If you are bleeding heavily or in severe pain your GP can refer you as an emergency to Branston Ward or 18 by contacting the doctor on call.
125.University College London Hospitals NHS Foundation Trust	University College Hospital NHS Trust, Elizabeth Garett Anderson Wing, Lower Ground Floor, 25 Grafton Way, London, WC1E 6DB	Monday to Friday, 9am – 12.30pm and 2pm – 3pm Christmas Eve and New Year's Eve (on weekdays), 9am – 1.30pm	Up to 14 weeks	Patients in early pregnancy do not need a referral: we operate a walk-in clinic. We generally see people who have walked in in the order in which they arrive, but priority will always be given to those who are found to be assessment. Our clinics can become extremely busy with wait times of over 4 hours. Urgent clinical queries should be directed to NHS over 4 hours. Urgent clinical queries should be directed to NHS lf you are pregnant and start to have severe pain and/or very heavy bleeding at night, over the weekend or on a bank holiday, please call NHS 111 for advice, or go straight to Accident & Emergency. We are able to see women in early pregnancy on Saturday and Sunday between 9am and 12:30pm, but they must attend A&E first.  https://www.uclh.nhs.uk/our-services/find-service/womens-health-1/gynaecology/gynaecology-diagnostic-and-treatment-unit
126.University Hospital Southampton	Princess Anne Hospital, Coxford Road, Southampton, SO16 5YA	Not found	Up to 21weeks	takes referrals from GPs and the emergency department by a process of booked appointments. https://www.uhs.nhs.uk/departments/gynaecology
127.University Hospitals Birmingham NHS Foundation Trust	Good Hope Hospital, Rectory Road, Sutton Coldfield, B75 7RR	Clinics are held every weekday (Monday to Friday) from 09.00 hours to	Up to 15 weeks	Attendance is by appointment only https://hgs.uhb.nhs.uk/gynaecology-directory-of-services/#:~:text=Early%20Pregnancy%20Unit%20%E2%80%93%20is%20a,a%20day%20case%20hyeremesis%20unit.

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
128.University Hospitals Birmingham NHS Foundation Trust	Heartlands Hospital, Bordesley Green East, Birmingham, B9 5SS	24 hours / 7 days	Not found	A 24/7 emergency area that specialises in early pregnancy complications, it consists of 2 scan rooms, 2 treatment rooms, 2 consultation rooms, an MVA bay & a day case hyperemesis unit. https://hgs.uhb.nhs.uk/gynaecology-directory-ofservices/#:~:text=Early%20Pregnancy%20Unit%20%E2%80%93%20is%20a,a%20day%20case%20hyeremesis%20unit.
129. University Hospitals Bristol NHS Foundation Trust	St. Michael's Hospital, Southwell Street, Bristol, BS2 8EG	EPAC is open to referrals and queries Mon - Fri 8:30am to 16:00pm.	5 - 18 weeks	The clinic provides emergency assistance for women with suspected miscarriage or ectopic pregnancy who have a positive pregnancy test with bleeding and/or pain. This is not a drop-in clinic, we operate an appointment system. Please arrange a referral from your midwife, GP or A&E. Patients are seen in Clinic between 9:00am and 13:00pm according to their booked arrival time. The weekend service is shared with Southmead Hospital. This means that sometimes we are closed on Saturday and Sunday. The health professional referring you will be able to give you more advice.  https://www.uhbristol.nhs.uk/patients-and-visitors/your-hospitals/st-michaels-hospital/what-we-do/early-pregnancy-assessment-clinic/
130.University Hospitals Coventry & Warwickshire NHS Trust	University Hospitals Coventry & Warwickshire, Clifford Bridge Road, Coventry, CV2 2DX	7 days a week and 24 hours a day	Up to 20 weeks	EGU is an emergency unit that cares for patients <20/40 gestation with pain, bleeding or other complications and patients with gynaecological emergencies such as sudden onset of bleeding, abdominal pain, cysts and other gynaecological emergencies. EGU utilises the same principles as Emergency Department (ED) where patients should be seen within four hours.  https://www.uhcw.nhs.uk/our-services-and-people/our-departments/gynaecology/
131.University Hospitals Dorset NHS Foundation Trust	Dorset County Hospital, Williams Avenue, East Wing, Outpatient Department, Dorchester, DT1 2JY	Our appointments are in the mornings.	6 - 14 weeks	There is an Early Pregnancy Unit located at each of the three main hospitals in Dorset. Not a walk-in service, but happily accept referrals from GPs, Emergency Departments, midwives and other healthcare professionals.
132.University Hospitals Dorset NHS Foundation Trust	Poole Hospital NHS Trust, Longfleet Road, Poole, BH15 2JB	Our appointments are in the mornings.	6 - 14 weeks	There is an Early Pregnancy Unit located at each of the three main hospitals in Dorset. Not a walk-in service, but happily accept referrals from GPs, Emergency Departments, midwives and other healthcare professionals.

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
133.University Hospitals Dorset NHS Foundation Trust	Royal Bournemouth Hospital, Castle Lane East, Early Pregnancy Assessment Unit, Women's Health Unit, Bournemouth	Our appointments are in the mornings.	6 - 14 weeks	There is an Early Pregnancy Unit located at each of the three main hospitals in Dorset. Not a walk-in service, but happily accept referrals from GPs, Emergency Departments, midwives and other healthcare professionals. https://maternitymattersdorset.nhs.uk/pregnant/epu/
134. University Hospitals of Derby and Burton (See also Sherwood Forest Hospitals NHS Foundation Trust)	Royal Derby Hospital, Uttoxeter Rd, Derby, DE22 3NE	Monday to Friday: 9am – 6:30pm Saturday, Sunday and Bank Holidays: 9am - 4:30pm	Up to 16 weeks	The Gynaecology Assessment Unit (GAU) provides a rapid assessment and diagnostic service for all emergency patients and <b>incorporates an early pregnancy assessment service</b> . Referrals can be made by GPs, midwives, A+E and other community services. The Maternity Assessment Unit cares for women from 16 weeks onwards and is situated in Queens Hospital Burton. Reasons for referral to MAU include Reduced fetal movements, Raised blood pressure or proteinuria, <b>Abdominal pain or bleeding in pregnancy (if you are less than 16 weeks your midwife or GP can contact the gynaecology department for you)</b> , Labour, Spontaneous ruptured membranes (waters have broken). Appointment times are not given. Women are seen on a priority basis. https://www.thesurgeryashbourne.co.uk/appointmentstest-referrals/self-referral-services/pregnancy-assessment-unit-pau-in-derby/
135.University Hospitals of Leicester NHS Trust	Leicester General Hospital, Leicester General Hospital, Gwendolen Rd, Leicester LE5 4PW	Not found	less than 16 weeks	if you are less than 16 weeks pregnant and have any bleeding you need to contact your GP who will advise you and who can also refer you in to the Early Pregnancy Assessment Service at either Leicester Royal Infirmary or Leicester General Hospital if it is felt further assessment or a scan is required. Out of GP hours you can phone 111 for advice. If you experience bleeding from 16 weeks onwards you can contact the Maternity Assessment Unit (MAU) at the hospital where you are booked direct and a midwife will advise you and invite you to come in for assessment if appropriate. The MAU's phone numbers are there 24/7 for advice. https://www.leicestermaternity.nhs.uk/antenatal/problems-in-pregnancy/
136.University Hospitals of Leicester NHS Trust	Leicester Royal Infirmary, Infirmary Square, Leicester, LE15WX	Not found	less than 16 weeks	If you are less than 16 weeks pregnant and have any bleeding you need to contact your GP who will advise you and who can also refer you in to the Early Pregnancy Assessment Service at either Leicester Royal Infirmary or Leicester General Hospital if it is felt further assessment or a scan is required. Out of GP hours you can phone 111 for advice. https://www.leicestermaternity.nhs.uk/antenatal/problems-in-pregnancy/
137.University Hospitals of Morecambe Bay	Royal Lancaster Infirmary, Ashton	Not found	Up to 18 weeks	Care of women undergoing fetal loss Up to 18 weeks gestation. https://www.uhmb.nhs.uk/our-services/services/gynaecology

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
NHS Foundation Trust	Road, Lancaster, LA1 4RP			
138.University Hospitals of North Midlands NHS Trust	Royal Stoke University Hospital, Newcastle Road, Stoke on Trent, ST4 6QG	Not found	Up to 16 weeks	Patients are referred to the unit by the clinician whose care they are under. Please note that self-referrals are not accepted. https://www.uhnm.nhs.uk/our-services/maternity/royal-stoke-university-hospital/
139.University Hospitals Plymouth NHS Trust	Derriford Hospital, Derriford Road, Level 6 Maternity Unit, Plymouth, PL6 8DH	Not found	6 - 16 weeks	Women with early pregnancy problems can be referred to a dedicated Early Pregnancy Unit that provides efficient and compassionate management, counselling and access to appropriate information. You can be referred to EPU by any of the gynaecology team or by your GP/primary care clinician or ED. We are sorry that self-referrals are not accepted unless you have previously had an ectopic and are at least 6 weeks pregnant.  https://www.plymouthhospitals.nhs.uk/early-pregnancy-problems https://www.plymouthhospitals.nhs.uk/gynaecology
140.University Hospitals Sussex NHS Foundation Trust	Princess Royal Hospital, Lewes Road, Haywards Heath, RH16 4EX	Monday, Wednesday and Friday 8:30 am to 12:00 pm	5 - 14 weeks	Not a walk-in clinic. If your doctor or midwife thinks you need to be seen by us, they will refer you and making an appointment on your behalf. You can self-refer if you have had a previous ectopic or molar pregnancy. https://www.uhsussex.nhs.uk/services/maternity/pregnancy/early-pregnancy-unit/
141.University Hospitals Sussex NHS Foundation Trust	Royal Sussex County Hospital, Eastern Road, Brighton, BN2 5BE	Monday to Friday 8:00 am to 6:00 pm	5 - 14 weeks	Not a walk-in clinic. If your doctor or midwife thinks you need to be seen by us, they will refer you and making an appointment on your behalf. You can self-refer if you have had a previous ectopic or molar pregnancy. https://www.uhsussex.nhs.uk/services/maternity/pregnancy/early-pregnancy-unit/
142.University Hospitals Sussex NHS Foundation Trust	St Richard's Hospital, Spitalfield Lane Chichester West Sussex PO19 6SE	Monday to Friday 8:30 am to 12:30 pm	5 - 14 weeks	Not a walk-in clinic. If your doctor or midwife thinks you need to be seen by us, they will refer you and making an appointment on your behalf. You can self-refer if you have had a previous ectopic or molar pregnancy. https://www.uhsussex.nhs.uk/services/maternity/pregnancy/early-pregnancy-unit/
143.University Hospitals Sussex NHS Foundation Trust	Worthing Hospital, Lyndhurst Road, Worthing, BN11 2DH	Mon to Fri 8:00 am to 2:00 pm. From 2:00pm to 7.30pm please contact the Gynaecology Day Unit.	5 - 14 weeks	Not a walk-in clinic. If your doctor or midwife thinks you need to be seen by us, they will refer you and making an appointment on your behalf. You can self-refer if you have had a previous ectopic or molar pregnancy.  https://www.uhsussex.nhs.uk/services/maternity/pregnancy/early-pregnancy-unit/

Other Information	The Early Pregnancy Assessment Unit (EPAU) sees women in early pregnancy Up to 19 +6 weeks who are experiencing problems such as bleeding, pain, vomiting, any other early pregnancy problems. Specialist Early Pregnancy nurses offer assessment scans usually in a one stop approach. All options are provided for miscarriage and ectopic pregnancy including surgical management under local anaesthetic. The service also provides a hyperemesis day unit for ambulatory (outpatient) management of nausea and vomiting in pregnancy. All staff are trained in giving supportive patient-centred care including bereavement support. The unit also sees gynaecology emergency patients and offers rapid assessment and scans with access to seven day, twenty four emergency gynaecology care. <a <="" href="https://www.walsallheaithcare.nhs.uk/our-services/maternity/early-pregnancy-assessment-unit-epau/#:~:text=The%20Early%20Pregnancy%20Assessment%:00mit.in%20Unit.in%200ne%20one%20spproach." th=""><th>reeks Please contact your midwife or GP for referral to EPAU as usual. All referrals will be triaged by EPAU staff and you may receive a telephone consultation to discuss your symptoms. You may not necessarily be invited to EPAU for a scan. https://whh.nhs.uk/services/maternity</th><th>We do not offer a self-referral service. Appointments can be made by GPs, from A&amp;E and by other healthcare professionals.  https://www.westhertshospitals.nhs.uk/ourservices/womens_services/gynaecology/epu/appointments.asp</th><th>Referral to EPAU is usually via your GP or midwife or via the emergency department. Women who have had a previous ectopic pregnancy can contact the department to arrange an appointment from six weeks into a new pregnancy. <a href="https://www.wsh.nhs.uk/Services-A-z/Gynaecology/Early-pregnancy-assessment-service.aspx">https://www.wsh.nhs.uk/Services-A-z/Gynaecology/Early-pregnancy-assessment-service.aspx</a></th><th>This service is accessed via a referral system only. Referrals may be made from the Emergency department (ED), GP and midwives. Women can contact EPAC directly for advice and support. Any woman with excessive bleeding and/or severe abdominal pain should attend the nearest ED (Weston ED is not open from 22.00 to 08.00). https://www.waht.nhs.uk/en-GB/Our-Services1/Hospital-Units/Ashcombe-Birth-Centre/Farly-Pregnancy-Assessment-Clinic-EPAC/</th></a>	reeks Please contact your midwife or GP for referral to EPAU as usual. All referrals will be triaged by EPAU staff and you may receive a telephone consultation to discuss your symptoms. You may not necessarily be invited to EPAU for a scan. https://whh.nhs.uk/services/maternity	We do not offer a self-referral service. Appointments can be made by GPs, from A&E and by other healthcare professionals.  https://www.westhertshospitals.nhs.uk/ourservices/womens_services/gynaecology/epu/appointments.asp	Referral to EPAU is usually via your GP or midwife or via the emergency department. Women who have had a previous ectopic pregnancy can contact the department to arrange an appointment from six weeks into a new pregnancy. <a href="https://www.wsh.nhs.uk/Services-A-z/Gynaecology/Early-pregnancy-assessment-service.aspx">https://www.wsh.nhs.uk/Services-A-z/Gynaecology/Early-pregnancy-assessment-service.aspx</a>	This service is accessed via a referral system only. Referrals may be made from the Emergency department (ED), GP and midwives. Women can contact EPAC directly for advice and support. Any woman with excessive bleeding and/or severe abdominal pain should attend the nearest ED (Weston ED is not open from 22.00 to 08.00). https://www.waht.nhs.uk/en-GB/Our-Services1/Hospital-Units/Ashcombe-Birth-Centre/Farly-Pregnancy-Assessment-Clinic-EPAC/
Gestation	Up to 20 weeks	Up to 18 weeks	6 - 13 weeks	from 6 weeks	Up to 20 weeks
Opening times	Monday to Friday 7.30am – 20:00pm (Booked scan clinic 08:35- 1400pm). Out of hours is managed on Ward 23.	Monday to Friday 0830 – 5pm	The Unit runs from Monday – Friday: 8.30 - 16.00 Scanning hours: 8.30 - 13.00	Monday-Friday 8:30am - 4:00pm	Open from 09.00 - 17.00 for advice and support. Ultrasound scans are
Hospitals providing Early Pregnancy Services	Walsall Manor Hospital, Moat Road, Walsall, West Midlands, WS2 9PS	Warrington Hospital, Lovely Lane, Women's Day Care Centre, Warrington, WA5 1QG	Watford General Hospital, Vicarage Road, Watford, Herts, WD18 0HB	West Suffolk Hospital, Hardwick Lane, Bury St Edmunds, Suffolk, IP33 2QZ	Weston General Hospital, Grange Road, Ashcombe Birth Centre, Weston-Super- Mare, BS23 4TQ
Trust	144.Walsall Healthcare NHS Trust	145.Warrington and Halton Teaching Hospitals NHS Foundation Trust	146.West Hertfordshire Teaching Hospitals NHS Trust	147.West Suffolk NHS Foundation Trust	148.Weston Area Health NHS Trust

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
		between 09.30 and 11.15.		
149.Whittington Health NHS Trust	Whittington Health NHS Trust, Magdala Avenue, London, N19 5NF	Monday to Friday from 8am to 6pm	Not found	Our emergency walk-in service for women experiencing problems during early pregnancy is available Monday to Friday from 8am to 6pm (outside of these hours patients who need urgent care will be seen in A&E). Women who experience problems or have concerns can walk-in and be seen by our specialist team without being referred by their GP or healthcare professional. This is an emergency service for pregnant women and operates in a similar way to our emergency department, with women triaged on arrival. Our consultants aim to see you as quickly as possible, however during busy times you can expect to wait between three and four hours to be seen. We usually assess and scan women on the same day, but on some occasions you may be assessed by our senior nurse or junior doctor and asked to return at another time for a scan if required. Please note that our walk-in service is only for women experiencing problems in early pregnancy.  #### ### ### ### ### ### ### ### ###
150.Wirral University Teaching Hospital NHS Foundation Trust	Wirral Women & Children's Hospital Arrowe Park Rd Birkenhead Merseyside, Wirral CH49 5PE	7.30am to 8pm	Up to 17 weeks	Assessment is by appointment only. Patients need to be referred by their GP or other Health Professional e.g. Accident & Emergency, Walk-in Centre, Midwife, Consultant or from the Gynaecology Ward. We aim to provide an ultrasound scan within 72 hours.  Early Pregnancy Unit   Wirral University Hospital NHS Foundation Trust (wuth.nhs.uk)
151.Worcestershire Acute Hospitals NHS Trust	Worcester Royal Hospital, Newtown Road, Charles Hasstings Way, Worcester, WR5 1DD	Not found	Up to 16 weeks	The EPAU service is a countywide service with clinics at Worcester, Redditch and Kidderminster. Once you have been referred by your health care professional you will either receive an appointment time immediately or alternatively be contacted by our EPAU service during the next working day and, if appropriate, they will offer you an appointment within 48 hours of referral at one of our countywide clinics. https://www.worcsacute.nhs.uk/services/item/gynaecology

Trust	Hospitals providing	Opening times	Gestation	Other Information
	Early Pregnancy Services			
152.Worcestershire Acute Hospitals NHS Trust	Kidderminster Hospital, Bewdley Road, Kidderminster DY11 6RJ	Not found	Up to 16 weeks	The EPAU service is a countywide service with clinics at Worcester, Redditch and Kidderminster. Once you have been referred by your health care professional you will either receive an appointment time immediately or alternatively be contacted by our EPAU service during the next working day and, if appropriate, they will offer you an appointment within 48 hours of referral at one of our countywide clinics. https://www.worcsacute.nhs.uk/services/item/gynaecology
153.Worcestershire Acute Hospitals NHS Trust	Alexandra Hospital, Woodrow Drive, Redditch, B98 7UB	Not found	Up to 16 weeks	The EPAU service is a countywide service with clinics at Worcester, Redditch and Kidderminster. Once you have been referred by your health care professional you will either receive an appointment time immediately or alternatively be contacted by our EPAU service during the next working day and, if appropriate, they will offer you an appointment within 48 hours of referral at one of our countywide clinics.
154.Wrightington, Wigan and Leigh Teaching Hospitals NHS Foundation Trust	Leigh Infirmary, The Avenue, Ward 2, Leigh, WN7 1HS	Mon - Fri, 9- 12:00	Not found	You can self-refer to the service. https://www.wwl.nhs.uk/antenatal-information
155.Wye Valley NHS Trust	Hereford County Hospital, Union Walk, Hereford, HR1 2ER	Mon - Fri, 8:30 - 5:00	6 - 18 weeks	If you do not already have an appointment a member of the team will ring you with a date and time. We aim to see you within 2 working days. <a href="https://www.wyevalley.nhs.uk/media/858449/early-pregnancy-assessment-unit.pdf">https://www.wyevalley.nhs.uk/media/858449/early-pregnancy-assessment-unit.pdf</a>
156.Yeovil Hospital Healthcare	Yeovil Hospital, Higher Kingston, Yeovil, Somerset, BA21 4AT	7 days a week either through EPAU or GAU	6 - 15 weeks	Early Pregnancy Assessment Clinic (EPAC) - We recommend that if you are experiencing pain, bleeding or spotting, loss or pregnancy symptoms, if you have previously had an ectopic pregnancy, or have sharp one-sided pain and/or pain in your shoulders or feel very faint or dizzy that you contact your GP, Community Midwife or Emergency Department who will refer you to EPAC if required. You may also be referred to this clinic if you are pregnant and have previously had an ectopic pregnancy or tubal surgery. If you are experiencing these symptoms it doesn't always mean that you will miscarry but we do recommend that you are referred to our Early Pregnancy. If you are experiencing any heaving bleeding or more pain that you can cope with please attend the Emergency Department. https://yeovilhospital.co.uk/services/gynaecology/

Trust	Hospitals providing Early Pregnancy Services	Opening times	Gestation	Other Information
157.York and Scarborough Teaching Hospitals NHS Foundation Trust	Scarborough General Hospital, Woodlands Drive, Scarborough, YO12 6QL	Not found	Not found	In the Women's Unit. Your GP or midwife may refer you to the unit. You may also be referred by an emergency nurse practitioner, out of hours GP or A&E. Women with a history of ectopic pregnancy may self-refer to EPAU. https://www.yorkhospitals.nhs.uk/our-services/a-z-of-services/womens-unit-scarborough-hospital/
158.York and Scarborough Teaching Hospitals NHS Foundation Trust	York Hospital, Wigginton Road, York, YO31 8HE	Monday to Sunday 08:00 to 13:00	6 - 16 weeks	The unit does not take self-referrals or walk-ins, if you are not under the care of the EPAU, please contact your GP or other healthcare professional. GPs, A&E and other health services may refer to this unit by contacting the early pregnancy assessment unit directly or via switchboard. Appointments: Reviews are by appointment only and we have capacity of Up to 7 people per day. While we aim to see you at your appointment time there may be a delay if an emergency comes Up. https://www.yorkhospitals.nhs.uk/our-services/a-z-of-services/womens-health/early-pregnancy-assessment-uniteepau/#:~:text=The%20Early%20Pregnancy%20Assessment%20Init%20is%20and%20isx%20and%20isxteen%20nurse%2Drun%2C%20Consultant,between%20six%20and%20isxteen%20weeks).

# Annex D. Guideline for Prescribing and Administration of Acute Pain Relief and Anti-emetics in Pregnancy in the Emergency Department and Urgent Care

This guideline was developed with the support of The Mariposa Trust (Saying Goodbye).

# **Summary**

This guideline brings together the information to effectively manage pregnant women with acute pain and nausea/vomiting across the Emergency Department and Urgent Care. This covers the prescribing, monitoring and administration of medication to pregnant women in acute pain.

#### Introduction

Pregnant women can experience pain for a number of reasons, from injury to pregnancy ligament issues through to miscarriage and labour. A clear pathway of pain relieving choices is needed within the Urgent Care setting.

The anti-emetics are documented in the Early Treatment of Hyperemesis Guideline but it is prudent to group these medications together as the indications often co-present.

#### Safety of Medicines in Pregnancy:

In general, the use of medications in pregnancy should be avoided where possible, particularly in the first trimester. The use of all medications in pregnancy should follow a careful risk versus benefit assessment. It should be noted that the data available to support prescribing decisions in pregnancy are usually of limited quantity and quality. The choices of medication within this guideline have been made bearing in mind the current safety data available.

Women will obviously have some concerns about the use of medication in pregnancy so <u>UKTIS</u> <u>BUMPS</u> provide some very good leaflets to allow them to make an informed decision.

#### Target Groups (s) or Disease Processes (es)

Pregnant women presenting to the Emergency Department with acute pain and/or nausea and vomiting. This is to include pregnant women presenting with miscarriage, either threatened or inevitable.

# Professional Groups (s)

All registered nurses, paramedics and medical staff who prescribe and administer pain relief or antiemetics in the Emergency Department or Urgent Care.

# Clinical Guidelines

Pain Relief for Pregnancy and Threatened Miscarriage

All pain relief used in pregnancy should follow a careful risk versus benefit assessment and should be prescribed as the lowest possible dose and for the shortest possible duration.

For women with threatened miscarriage, an increase in pain should be anticipated and consideration should be given for a supply of medication to cope with this.

#### Table 1: Pain Relief for Pregnancy in 1st Trimester (Including Threatened Miscarriage)

1st Trimester - to 11 weeks 6days

If possible, avoid all drugs during first trimester – non-pharmacological interventions should be considered first				
Pain severity	Drug	Dose		
Mild/Moderate	Paracetamol	1g qds PO/IV (if ≤50kg then 1g tds)		
	AND/OR			
	Ibuprofen (do not use if PV bleeding or threatened miscarriage)	200-400mg PO tds		
Moderate (not controlled by mild/moderate options)	Paracetamol + Codeine	Paracetamol PO/IV1g qds (if ≤50kg then 1g tds) PLUS		
	OR	Codeine PO 30mg qds		
		(OR Co-codamol 30/500mg PO 1 tablet qds or tds if $\leq$ 50kg)		
	Ibuprofen + Codeine (do not use if PV bleeding or	Ibuprofen 200-400mg PO tds PLUS		
	threatened miscarriage)	Codeine PO 30mg qds		
Severe	Morphine	PO 10-20mg every 4hours		
	(an anti-emetic must be prescribed with morphine)	IV 10mg every 4hours		

Table 2: Pain Relief for Pregnancy in 2nd Trimester (Including Threatened Miscarriage and Labour)

2 <sup>nd</sup> Trimester – 12 weeks to 27 weeks				
Pain severity	Drug	Dose		
Mild/Moderate	Paracetamol	1g qds PO/IV (if <50kg then 1g tds)		
	AND/OR			
	Ibuprofen – less than 20 weeks only (do not use if PV bleeding or threatened miscarriage)	200-400mg PO tds		
	AND/OR			
	Entonox (from 16 weeks)	PRN		
Moderate (not controlled by	Paracetamol + Codeine	Paracetamol PO/IV 1g qds (if ≤50kg then 1g tds) PLUS		
mild/moderate options)		Codeine PO 30mg qds		
οριιστισ)		(OR Co-codamol 30/500mg PO 1 tablet qds or tds if < 50kg)		
	OR			
	Ibuprofen + Codeine – less than 20 weeks only (do not use ibuprofen if PV bleeding or threatened miscarriage)	Ibuprofen ( <b>Less than 20 weeks only</b> ) 200-400mg PO tds PLUS		

		Codeine PO 30mg qds	
	Entonox (from 16 weeks)	PRN	
Severe Entonox (from 16 weeks)		PRN	
	Morphine (an anti-emetic must	PO 10-20mg every 4hours	
	be prescribed with morphine)	IV 10mg every 4hours	

Table 3: Pain Relief for Pregnancy and Labour in 3rd Trimester

3 <sup>rd</sup> Trimester - >28 weeks  NOTE: Neonatal monitoring for symptoms of withdrawal may be warranted following maternal use of opioids near term				
Mild/Moderate	Paracetamol	1g qds PO/IV (if ≤50kg then 1g tds)		
	AND/OR			
	Entonox	PRN		
Moderate (not controlled by	Paracetamol + Codeine	Paracetamol PO/IV 1g qds (if ≤50kg then 1g tds) PLUS		
mild/moderate options)		Codeine PO 30mg qds		
	AND/OR	PRN		
	Entonox			
Severe	Entonox	PRN		
	AND/OR			
	Morphine (an anti-emetic must	PO 10-20mg every 4hours		
	be prescribed with morphine)	IV 10mg every 4hours		

# Pain Relief in Inevitable Miscarriage:

Pain is closely linked with emotion and due to this, in inevitable miscarriage, the pain may not seem to be in proportion to the gestation of the pregnancy. The choice of pain relief must be linked to the patient's need and not to the pregnancy gestation.

Table 4: Pain Relief in Inevitable Miscarriage

Severity	Drug	Dose
All	Entonox	PRN
Mild/Moderate	Paracetamol	1g qds PO/IV (if ≤50kg then 1g tds)
Moderate	Codeine (only use in addition to paracetamol)	30-60mg PO qds
Severe	Morphine (an anti-emetic must be prescribed with morphine)	PO 10-20mg every 4hours

	IV 10mg every 4hours

# Pain Relief in Labour:

Please see Trust guidelines <u>Pre-term Labour and Birth</u> and <u>Intrapartum Care of healthy Women and Babies during Childbirth</u>.

#### Anti-emetics:

These licensed medicines are being used for an unlicensed indication but recommended for use in secondary care. Patients must be made aware of this and the available evidence on safety in pregnancy when they are prescribed and a note made in their notes to record this. Non-pharmacological options can be recommended including taking ginger or using acupressure therapies (including 'travel bands' or 'sea-bands').

Anti-emetics must be co-prescribed with opioids.

Choice of anti-emetic should be 'step-wise' from 1st line upwards.

**Table 5: Anti-emetics in Pregnancy** 

	Anti-emetic	Dose	Routes	Contraindications / Cautions	Pharmacokinetic s
				CI: Alcohol intoxication Cautions: Glaucoma, Urinary retention,	Onset of action: Oral: 2hrs
					IV: 20mins
1 <sup>st</sup> line	Cyclizine (antihistamine)	50mg TDS	PO/IV/I M	Porphyria, Severe Heart Failure or acute	Duration of action:
	,			MI, Hx of cyclizine abuse, Lactose	Oral: 4hrs
				intolerant (tablets)	IV: No information
				NB: Injection is painful	on duration of action
					Onset of action:
		12.5mg		CI: Epilepsy,	IM: 10-20mins
		IM 8		Myasthenia Gravis, Stroke risk factors,	Oral: 30-60mins
		hourly Or	IM	Narrow angle glaucoma, Deranged I FT	Peak effect (oral): 2-4hrs
1 <sup>st</sup> line	Prochlorperazin e (phenothiazines)	5-10mg PO 6 – 8 hourly	PO	Cautions: Monitor for EPS*, avoid sunlight, causes postural	Duration of action (oral/IM): 3- 4hrs
		Or 3-6mg Buccal 12 hourly	Buccal	hypotension, monitor WCC for agranulocytosis, Lactose intolerant (5mg tablets only)	Buccal: No information on onset of action, peak effect or duration of action
2 <sup>nd</sup> line (in additio n to	Metoclopramide (for a maximum of 5 days**)	5-10mg TDS (total maximum	PO/IV/I M	CI: Phaeochromocytomia, Methaemogrebinaemia , Hx of neuroleptic or	Onset of action: IV: 1-3mins

first line)		per 24hrs 0.5mg/kg or 30mg whicheve r is lowest)		metoclopramide- induced tardive dyskinesia, Epilepsy, Breast feeding, Porphyria  Caution: Monitor for EPS*, Hx of hypertension, hx of cardiac disorders, Renal or Hepatic impairment (decrease dose – see www.medicines.org.uk ), Lactose intolerant (tablets)	Oral: 30-60mins  Peak effect:  IV: 15mins  Oral: 1-2hrs  Duration of action (oral/IV): 1-2hrs
2 <sup>nd</sup> line (in additio n to first line)	Ondansetron ***	4 – 8mg PO 6 – 8 hourly Or 8mg over 15mins IV 12 hourly	PO/IV	CI: Co-administration with domperidone Caution: Cardiac issues including Congenital Long QT Syndrome, Hepatic impairment (Decrease total daily dose to 8mg)	Onset of action: Oral: 30mins IV: No information Peak effect: IV: 10mins Oral 1.5-2.2hrs
2nd line	Domperidone*** *	10mg TDS	PO	CI: Moderate/severe Hepatic impairment, Hx of prolongation cardiac conduction intervals, Co-administration of QT prolongation drugs (including Ondansetron), Co- administration of CY3A4 inhibitors Caution: Renal impairment (decrease dose frequency), Lactose intolerant	Peak effect: 30- 60mins No information on duration of action

# \*Extra-Pyramidal Side Effects:

Initial symptoms of restlessness, agitation, malaise, or a fixed stare. Characteristically, there are muscular spasms of neck – torticollis, eyes – oculogyric crisis, tongue, or jaw. May occur with Prochlorperazine and Metoclopramide.

# <u>Treatment is with Procyclidine 5mg IM/IV and Prochlorperazine and/or Metoclopramide should</u> be stopped immediately

Combinations of different drugs can be considered for women who do not respond to a single antiemetic.

<sup>\*\*</sup>Metoclopramide: MRHA alert limits supply to 5/7 due to risks of neurological effects

<sup>\*\*\*</sup>Ondansetron: MHRA alert that there is a small increase in risk of oral cleft abnormalities with use of ondansetron in under 12/40 (3 in 10,000). The patient must be informed of the risk and this must be a consideration in the 2<sup>nd</sup> line medication choice.

<sup>\*\*\*\*</sup> Domperidone: MRHA alert to risk of cardiac side effects

#### References/Bibliography

Department of Health (2021). NHS Constitution: the NHS belongs to us all. [online]. London. Department of Health. Available from

https://www.gov.uk/government/uploads/system/uploads/attachment\_data/file/170656/NHS\_Constitution.pdf [Accessed 18/11/21]

Babb M, Koren G, Einarson A. (2010) Treating pain in pregnancy Can Fam Physician 56:25-26

Codeine or Dihydrocodeine in pregnancy (2015) UK Teratology Information Service Version 1 (Accessed via Toxbase <a href="https://www.toxbase.org/">www.toxbase.org/</a> 18/11/21)

FDA (2020) Avoid use of NSAIDs in Pregnancy at 20 weeks or later because they can result in low amniotic fluid www.fda.gov Accessed 4/1/2020

Morphine in pregnancy (2021) UK Teratology Information Service Version 3 (Accessed via Toxbase <a href="https://www.toxbase.org/">www.toxbase.org/</a> 18/11/21)

Nausea and vomiting in pregnancy (2019) UK Teratology Information Service Version 2.0 (Accessed via Toxbase <a href="https://www.toxbase.org/">www.toxbase.org/</a> 18/11/21)

NGH-GU-1141 (2020) Management of Miscarriage Guideline Version 2

NICE NG126 (2019) Ectopic pregnancy and miscarriage: diagnosis and initial management

NICE CG190 (2017) Intrapartum care for healthy women and babies

NSAIDs in pregnancy (2019) UK Teratology Information Service Version 3 (Accessed via Toxbase <a href="https://www.toxbase.org/">www.toxbase.org/</a> 18/11/21)

Paracetamol in pregnancy (2017) UK Teratology Information Service Version 1.8a (Accessed via Toxbase www.toxbase.org/ 18/11/21)

RCEM Best Practice Guideline (2021) Management of Pain in Adults

RCOG (2016) The Management of Nausea and Vomiting of Pregnancy and Hyperemesis Gravidarum Green Top Guideline No.69

UKMI (2020) Can opioids be used for pain relief in pregnancy Medicines Q&As

# **Guidance Development**

The guideline was developed in view of current evidence. The guideline will be updated every 3 years unless an earlier review is indicated through a change in evidence.

The Medical Director, Urgent Care/Emergency Department Matron and Ward Managers are responsible for ensuring that their staff are made aware of the updated guideline and ensure staff are aware of how to access the guideline.

The guideline has been reviewed against the Equality & Diversity Screening Tool and a full Impact Assessment undertaken if necessary

#### Audit

Exception reporting on DATIX. This is auditing of all medication related incidents within the Emergency/Urgent Care department and patterns related to this guideline.

Pharmacy Audit: Appropriate pain relief and anti-emetics prescribed for pregnant women. This will be audited for our pregnant patients within the Emergency/Urgent Care department within the program of medication audits.

#### **Implementation & Training**

Information of change on A&E Pharmacy notice board

Made aware at clinical meeting and Doctors/Nurses meetings once uploaded onto intranet

#### **Appendices**

# Appendix 1 Paracetamol: Cautions and Contra-indications

Care is advised in the administration of paracetamol to patients with severe renal or severe hepatic impairment. The hazard of overdose is greater in those with non-cirrhotic alcoholic liver disease.

Do not take with any other paracetamol-containing products.

# Appendix 2 Ibuprofen: Cautions and Contra-indications

Hypersensitivity to Ibuprofen or any of the constituents in Ibuprofen tablets.

Patients who have previously shown hypersensitivity reactions (e.g. asthma, rhinitis, angioedema or urticaria) in response to aspirin or other non-steroidal anti-inflammatory drugs.

Active or history of recurrent peptic ulcer/haemorrhage (two or more distinct episodes of proven ulceration or bleeding).

History of gastrointestinal bleeding or perforation, related to previous NSAIDs therapy.

Ibuprofen should not be given to patients with conditions involving an increased tendency to bleeding Severe hepatic failure, renal failure or severe heart failure (NYHA Class IV)

Patients with rare hereditary problems of galactose intolerance, the Lapp lactase deficiency or glucose-galactose malabsorption should not take this medicine.

As with other NSAIDs, ibuprofen may mask the signs of infection.

The use of Ibuprofen with concomitant NSAIDs, including cyclooxygenase-2 selective inhibitors, should be avoided due to the increased risk of ulceration or bleeding.

Caution should be advised in patients receiving concomitant medications which could increase the risk of ulceration or bleeding, such as oral corticosteroids, anticoagulants such as warfarin, selective serotonin-reuptake inhibitors or anti-platelet agents such as aspirin

NSAIDs should be given with care to patients with a history of ulcerative colitis or Crohn's disease as these conditions may be exacerbated

Caution is required if Ibuprofen is administered to patients suffering from, or with a previous history of, bronchial asthma or allergic disease since NSAIDs have been reported to precipitate bronchospasm in such patients.

Caution is required prior to starting treatment in patients with a history of hypertension and/or heart failure as fluid retention, hypertension and oedema have been reported in association with NSAID therapy.

Patients with uncontrolled hypertension, congestive heart failure (NYHA II-III), established ischaemic heart disease, peripheral arterial disease, and/or cerebrovascular disease should only be treated with ibuprofen after careful consideration and high doses (2400 mg/day) should be avoided.

Careful consideration should also be exercised before initiating long-term treatment of patients with risk factors for cardiovascular events (e.g. hypertension, hyperlipidaemia, diabetes mellitus, smoking), particularly if high doses of ibuprofen (2400 mg/day) are required.

Renal impairment as renal function may further deteriorate

There is a risk of renal impairment in dehydrated adolescents.

Hepatic dysfunction

In patients with systemic lupus erythematosus (SLE) and mixed connective tissue disorders there may be an increased risk of aseptic meningitis

Serious skin reactions, some of them fatal, including exfoliative dermatitis, Stevens-Johnson syndrome, and toxic epidermal necrolysis, have been reported very rarely in association with the use of NSAIDs. Patients appear to be at highest risk of these reactions early in the course of therapy, the onset of the reaction occurring within the first month of treatment in the majority of cases. Ibuprofen should be discontinued at the first appearance of skin rash, mucosal lesions, or any other sign of hypersensitivity.

# **Appendix 3** Codeine: Cautions and Contra-indications

Acute respiratory depression, hypersensitivity to codeine or other opioid analgesics or to any of the excipients, obstructive airways disease, liver disease, severe hepatic dysfunction, acute alcoholism.

Use should be avoided in patients with raised intracranial pressure or head injury (in addition to the risk of respiratory depression and increased intracranial pressure, may affect pupillary and other responses vital for neurological assessment).

Codeine is also contraindicated in conditions where inhibition of peristalsis is to be avoided, where there is a risk of paralytic ileus, where abdominal distension develops, or in acute diarrhoeal conditions such as acute ulcerative colitis or antibiotic associated colitis (e.g. pseudomembranous colitis) or diarrhoea caused by poisoning.

Codeine is contraindicated in women during breastfeeding

Also contraindicated in patients for whom it is known they are CYP2D6 ultra-rapid metabolisers. Not recommended for use in patients with acute asthma.

It should only be used with caution in those with renal or hepatic impairment, and in those with a history of drug abuse, or in patients with hypotension, hypothyroidism, prostatic hypertrophy, adrenocortical insufficiency, inflammatory or obstructive bowel disorders, urethral stricture, shock, convulsive disorders, myasthenia gravis. Discontinuation should be carried out gradually in patients who may have developed physical dependence, to avoid precipitating withdrawal symptoms.

Codeine is metabolised by the liver enzyme CYP2D6 into morphine, its active metabolite. If a patient has a deficiency or is completely lacking this enzyme an adequate therapeutic effect will not be obtained. However, if the patient is an extensive or ultra-rapid metaboliser there is an increased risk of developing side effects of opioid toxicity even at commonly prescribed doses. General symptoms of opioid toxicity include confusion, somnolence, shallow breathing, small pupils, nausea, vomiting, constipation and lack of appetite. In severe cases this may include symptoms of circulatory and respiratory depression, which may be life-threatening and very rarely fatal.

Opioid analgesics should be avoided in patients with biliary tract disorders or used in conjunction with an antispasmodic.

Administration of pethidine and possibly other opioid analgesics to patients taking a monoamine oxidase inhibitor (MAOI) has been associated with very severe and sometimes fatal reactions. If the use of codeine is considered essential, then great care should be taken in patients taking MAOIs or within 14 days of stopping MAOIs.

Alcohol should be avoided whilst under treatment with codeine.

#### Appendix 4 Morphine: Cautions and Contra-indications

Morphine Oral Solution is contraindicated in:

- patients known to be hypersensitive to morphine sulfate or to any other component of the product
- respiratory depression
- · obstructive airways disease
- · acute hepatic disease,
- · acute alcoholism,
- · head injuries
- coma
- · convulsive disorders
- · increased intracranial pressure
- · paralytic ileus
- · patients with known morphine sensitivity
- concurrent administration with monoamine oxidase inhibitors or within two weeks of discontinuation of their use
- patients with phaeochromocytoma. Morphine and some other opioids can induce the release of endogenous histamine and thereby stimulate catecholamine release
- · acute asthma exacerbations

Care should be exercised if morphine sulfate is given:

• in hypothyroidism, and where there is reduced respiratory function such as kyphoscoliosis, emphysema, cor pulmonale and severe obesity.

If constipation occurs, this may be treated with the appropriate laxatives. Care should be exercised in patients with inflammatory bowel disease.

The administration of morphine may result in severe hypotension in individuals whose ability to maintain homeostatic blood pressure has already been compromised by depleted blood volume or the concurrent administration of drugs such as phenothiazine or certain anaesthetics

Tolerance and dependence may occur. Withdrawal symptoms may occur on abrupt discontinuation or on the administration of a narcotic antagonist e.g. naloxone.

Morphine should be used with particular care in patients with a history of alcohol and drug abuse.

#### Risk in special populations

Morphine is metabolised by the liver and should be used with caution in patients with hepatic disease as oral bioavailability may be increased. It is wise to reduce dosage in chronic hepatic and renal disease, severe hypothyroidism, adrenocortical insufficiency, prostatic hypertrophy or shock. The active metabolite Morphine-6-glucoranide may accumulate in patients with renal failure, leading to CNS and respiratory depression.

#### **Appendix 5 Entonox: Cautions and Contra-indications**

Hypersensitivity to nitrous oxide

Patients who are unable to hold the mouth piece

Potential or confirmed pneumothorax

Severe injury to the face and jaw

Head injury, heavily sedated or intoxicated patient

Abdominal pain that could be a perforated bowel

Abdominal distension

Emphysema

Air embolism

Entrapped air following recent under water dive

Recent eye surgery with injection of intra-ocular gas

Patients with severe COPD

Psychiatric disturbances

Viable pregnancy up to 16 weeks gestation

Known vitamin B12 deficiency

Patient having received recent intraocular injection of gas

Suspected abuse of Entonox

#### Caution

with patients who are taking

Methotrexate (increased risk of toxicity)

Bleomycin (risk of pulmonary toxicity – use lowest dose possible)

Amiodarone (risk of pulmonary toxicity – use lowest dose possible)

Nitrofurantoin (risk of pulmonary toxicity – use lowest dose possible)

CNS depressant e.g. opiates, benzodiazepines (increased sedation)

# **Appendix 6 Cyclizine: Cautions and Contra-indications**

Hypersensitivity to the active substance or to any of the excipients listed in section

Cyclizine is contraindicated in the presence of acute alcohol intoxication. The anti-emetic properties of cyclizine may increase the toxicity of alcohol. There have been reports of abuse of cyclizine, either oral or intravenous, for its euphoric or hallucinatory effects.

As with other anticholinergic agents, it may precipitate incipient glaucoma and it should be used with caution and appropriate monitoring in patients with glaucoma, urinary retention, obstructive disease of the gastrointestinal tract, hepatic disease, pheochromocytoma, hypertension, epilepsy and in males with possible prostatic hypertrophy. It may have a hypotensive effect.

Cyclizine should be used with caution in patients with severe heart failure or acute myocardial infarction. In such patients, cyclizine may cause a fall in cardiac output associated with increases in heart rate, mean arterial pressure and pulmonary wedge pressure.

Cyclizine should be avoided in porphyria.

Case reports of paralysis have been received in patients using intravenous cyclizine. Some of the patients mentioned in these case reports had an underlying neuromuscular disorder. Thus intravenous cyclizine should be used with caution in all patients and with particular care in patients with underlying neuromuscular disorders.

# **Appendix 7 Prochlorperazine: Cautions and Contra-indications**

Hypersensitivity to the active substance or to any of the excipients

- Phaeochromocytoma.
- Patients with rare hereditary problems of galactose intolerance, the Lapp lactase deficiency or glucose-galactose malabsorption should not take this medicine, as it contains lactose.

- Prochlorperazine should be avoided in patients with liver or renal dysfunction, history of jaundice, Parkinson's disease, hypothyroidism, cardiac failure, myasthenia gravis, prostate hypertrophy. It should be avoided in patients known to be hypersensitive to phenothiazine or with a history of narrow angle glaucoma or agranulocytosis.
- Close monitoring is required in patients with epilepsy or a history of seizures, as phenothiazines may lower the seizure threshold.
- As agranulocytosis has been reported, regular monitoring of the complete blood count is recommended. The occurrence of unexplained infections or fever may be evidence of blood dyscrasia and requires immediate haematological investigation.
- It is imperative that treatment be discontinued in the event of unexplained fever, as this may be a sign of neuroleptic malignant syndrome (pallor, hyperthermia, autonomic dysfunction, altered consciousness, muscle rigidity). Signs of autonomic dysfunction, such as sweating and arterial instability, may precede the onset of hyperthermia and serve as early warning signs. Although neuroleptic malignant syndrome may be idiosyncratic in origin, dehydration and organic brain disease are predisposing factors.
- Because of the risk of photosensitisation, patients should be advised to avoid exposure to direct sunlight.
- To prevent skin sensitisation in those frequently handling preparations of phenothiazines, the greatest care must be taken to avoid contact of the drug with the skin
- Avoid concomitant neuroleptics.
- It should be used with caution in patients with cardiovascular disease or family history of QT prolongation. As with other neuroleptics, cases of QT interval prolongation have been reported with prochlorperazine very rarely. The risk-benefit should be fully assessed before prochlorperazine treatment is commenced, and patients with predisposing factors for ventricular arrhythmias, (e.g. cardiac disease; metabolic abnormalities such as hypokalaemia, hypocalcaemia or hypomagnesaemia; starvation; alcohol abuse; concomitant therapy with other drugs known to prolong the QT interval) should be carefully monitored (biochemical status and ECG), particularly during the initial phase of treatment.
- Acute withdrawal symptoms, including nausea, vomiting, sweating and insomnia have been described after abrupt cessation of antipsychotic drugs. Recurrence of psychotic symptoms may also occur, and the emergence of involuntary movement disorders (such as akathisia, dystonia and dyskinesia) has been reported. Therefore, gradual withdrawal is advisable.
- Cases of venous thromboembolism (VTE) have been reported with antipsychotic drugs. Since patients treated with antipsychotics often present with acquired risk factors for VTE, all possible risk factors for VTE should be identified before and during treatment with prochloperazine and preventative measures undertaken.
- Prochloperazine should be used with caution in patients with stroke risk factors.

#### **Appendix 8 Metoclopramide: Cautions and Contra-indications**

Hypersensitivity to the active substance or to any of the excipients

- Gastrointestinal haemorrhage, mechanical obstruction or gastro-intestinal perforation for which the stimulation of gastrointestinal motility constitutes a risk
- Confirmed or suspected pheochromocytoma, due to the risk of severe hypertension episodes
- History of neuroleptic or metoclopramide-induced tardive dyskinesia
- Epilepsy (increased crises frequency and intensity)
- Parkinson's disease
- Combination with levodopa or dopamineraic agonists

- Known history of methaemoglobinaemia with metoclopramide or of NADH cytochrome-b5 deficiency.
- Neurological Disorders: Extrapyramidal disorders may occur, particularly in young adults, and/or when high doses are used. These reactions occur usually at the beginning of the treatment and can occur after a single administration. Metoclopramide should be discontinued immediately in the event of extrapyramidal symptoms. These effects are generally completely reversible after treatment discontinuation but may require a symptomatic treatment (benzodiazepines in children and/or anticholinergic anti-Parkinsonian medicinal products in adults).

The time interval of at least 6 hours should be respected between each metoclopramide administration, even in case of vomiting and rejection of the dose, in order to avoid overdose. Prolonged treatment with metoclopramide may cause tardive dyskinesia, potentially irreversible.

Neuroleptic malignant syndrome has been reported with metoclopramide in combination with neuroleptics as well as with metoclopramide monotherapy. Metoclopramide should be discontinued immediately in the event of symptoms of neuroleptic malignant syndrome and appropriate treatment should be initiated.

Special care should be exercised in patients with underlying neurological conditions and in patients being treated with other centrally-acting drugs

There have been reports of serious cardiovascular undesirable effects including cases of circulatory collapse, severe bradycardia, cardiac arrest and QT prolongation following administration of metoclopramide by injection, particularly via the intravenous route

Special care should be taken when administering metoclopramide, particularly via the intravenous route, to patients with cardiac conduction disturbances (including QT prolongation), patients with uncorrected electrolyte imbalance, bradycardia and those taking other drugs known to prolong QT interval.

Intravenous doses should be administered as a slow bolus (at least over 3 minutes) in order to reduce the risk of adverse effects (e.g. hypotension, akathisia).

In patients with renal impairment or with severe hepatic impairment, a dose reduction is recommended

Patients with rare hereditary problems of galactose intolerance, the Lapp lactase deficiency or glucose-galactose malabsorption should not take this medicine

# **Appendix 9 Domperidone: Cautions and Contra-indications**

Domperidone is contraindicated in the following situations:

- In patients with moderate or severe hepatic impairment
- In patients who have known existing prolongation of cardiac conduction intervals, particularly QTc, patients with significant electrolyte disturbances or underlying cardiac diseases such as congestive heart failure
- Co-administration with QT-prolonging drugs, at the exception of apomorphine
- Co-administration with potent CY3A4 inhibitors (regardless of their QT prolonging effects)
- Known hypersensitivity to domperidone or any of the excipients.
- Prolactin-releasing pituitary tumour (prolactinoma.)
- Renal impairment

Domperidone should not be used when stimulation of gastric motility could be harmful: gastro-intestinal haemorrhage, mechanical obstruction or perforation.

Domperidone tablets contain lactose and may be unsuitable for patients with lactose intolerance, galactosaemia or glucose/galactose malabsorption.

### **Appendix 10 Ondansetron: Cautions and Contra-indications**

Hypersensitivity to ondansetron or to other selective 5-HT3-receptor antagonists (e.g. granisetron, dolasetron) or to any of their excipients

Concomitant use with apomorphine

Avoid ondansetron in patients with congenital long QT syndrome. Ondansetron should be administered with caution to patients who have or may develop prolongation of QTc, including patients with electrolyte abnormalities, congestive heart failure, bradyarrhythmias or patients taking other medicinal products that lead to QT prolongation or electrolyte abnormalities.

Caution should also be exercised in patients with cardiac rhythm or conduction disturbances and in patients treated with anti-arrhythmic agents or beta-adrenergic blocking agents.

Hypokalemia and hypomagnesemia should be corrected prior to ondansetron administration. If concomitant treatment with ondansetron and other serotonergic drugs is clinically warranted, appropriate observation of the patient is advised.

As ondansetron is known to increase large bowel transit time, patients with signs of sub-acute intestinal obstruction should be monitored following administration.

This medicinal product contains 3.6 mg sodium per ml of solution for injection. To be taken into consideration by patients on a controlled sodium diet.

# Annex E. Case Studies

# Case Study 1 - Ursula and Matt

Ursula was induced before 24 weeks gestation because doctors feared for her health should she continue with the pregnancy. She was unaware that when her baby was born, the baby showed signs of life. The medical staff and nurses present did not offer palliative care to the baby, focusing their attention exclusively on Ursula. Her husband Matt told of us that he had not been informed that his baby had been born alive and that he had discovered that his baby, who had been put to one side in a Moses basket, was breathing. Matt was not supported in seeing or spending time with his baby and the staff were unclear whether the baby should receive medical attention. He described feeling helpless. The baby survived for two hours, during which time Matt cradled him in his arms while Ursula was being attended to by physicians. This experience was extremely traumatic for both parents.

# Case Study 2 - Sarah & Adrian

On the 1 May 2016 myself and my husband went through the worst day of our lives. We lost our son Nate and I almost died. I was 18 weeks and five days pregnant. He was a miracle baby. After many years of trying, we were finally blessed through IVF.

We cannot fault the care we received while in the A&E department. They were truly amazing and if it was not for them I probably wouldn't be here today.

The problems started after I was moved to a ward. I was not taken to a bereavement suite, instead, I was taken to the gynaecology ward. The nurses were not trained to deal with our kind of situation. This was found out during the so-called investigation). I was told that a priest would be coming to speak with us (This did not happen).

The nurse who first treated me was amazing and took fabulous care of our son. The night nurses were very good as well. This all changed in the morning when there was a shift change. Nobody knew if I was staying or going. I was not examined by any doctors or consultants to check if I was ok. The staff were rude and nobody appeared to not know why I was there. When they finally decided I was going home it was all a rush to get me out. I was made to sign a form without my husband there with no explanation. I was offered no aftercare advice or counselling.

My husband and myself had requested a chance to say goodbye to Nate. They brought him in, in a coffin shaped cardboard box and put him on the table then left abruptly. Once we had said goodbye. The nurse then said and I quote "store IT between 2-8 in the fridge" placing her hand on Nate's box the nurse gave me an envelope and said it had my discharge papers in and left abruptly.

We gathered my things and left the room with no escort to the secure exit. We had to stand waiting for someone to buzz us out (no compassion). We then had to walk past the scan area for pregnant mums, down in the lift, past antenatal and outside down past the whole hospital holding Nate's box crying with everyone looking at us, while trying to maintain the correct temperature of him. We would have received better treatment in a vets it was DISGUSTING.

I somehow managed to pull myself together long enough to call a funeral home and explain what had happened. They were just as mortified as us. They acted very

quickly and came to collect Nate within a couple of hours. I will never forget the image of our little boy in that box in our fridge. It still haunts me now.

I wrote to the Chief Executive of the hospital. An investigation was supposedly carried out. All I kept getting from them was "we're really sorry, it's a learning curve". Not Acceptable.

I was offered a small number of counselling sessions, which helped a little but not very much. The last session was invaded by the person carrying out the investigation with supposed steps to be put in place, and a message from one of the nurses who had said "I will give up nursing and go back to my country". I felt they were trying to guilt me for something which was not my fault. They told me they would keep me updated on changes made (which they didn't). I even offered to come in and speak at midwifery training days of my experience, how to avoid it and what mothers and fathers who experience loss really need at this difficult time. (Never been invited in even though they said they would).

I have even taken my complaint to the Health Ombudsman, who carried out their own thorough investigation and they found the hospital at fault.

Even writing this now has been very difficult and a lot of tears have fallen, but I feel it is very important for people to hear our story as I DO NOT want anyone else to ever have to experience what we went through.

# Case Study 3 – Charlotte Ross

In the summer of 2021 I had a failed twin pregnancy. This was my sixth pregnancy all previous had ended in miscarriage.

In this last pregnancy I was bleeding from week 4 until week 14. I was under the EPAU and was scanned regularly. My scans showed a twin pregnancy but one twin did not grow/progress. I had previously experienced a failed twin pregnancy which led to both being lost one at 6 weeks, one at 10.

I had multiple contacts with the nursing staff and doctors and I had asked them what I should do if I passed my baby. I was told by each of them to keep the baby in Tupperware pot in my fridge and to call the ward in office hours so they can arrange a time for me to take them in so they can be sent for genetic testing etc.

Luckily this was not needed for me this time and I went into have a successful pregnancy. I was shocked that this was even suggested and that there is such little regards for the babies. I have friends who have attended different healthcare trusts for similar and they have had totally different experiences.

My local trusts early pregnancy and anti-natal care was such a disappointment, which is a great shame as I also work for them as a senior nurse in emergency care. Normally I can put my nurse hat on and rationalise when things that happen are less than ideal. With this I am at a loss and cannot understand why it would even be suggested.

Very disappointing to see this is a widespread issue, I hope that some guidance can be issued from this so it can stop happening.

# Case Studies 4-6 were gained from a consultation with the MAMTA focus group.

## Case Study 4 – Salma

I've had 16 miscarriages and 4 stillbirths - "I just have to be strong and keep going"

It's not nice seeing my sisters and brothers come home with a baby when I didn't - I lost a baby at the same time as my sister gave birth and going home was hard to hear the new baby crying

"My Faith has got me through it - In my religion (Islam) – when you have lost a baby - you have to be patient, you have to say thanks to God - it's difficult"

"The men don't support you when it's a miscarriage – they take it as such a small issue, like it's a blood clot"

"My family burnt the pictures - It's hard not seeing the photos — I carried one baby for 33 weeks - did he look like me?"

"No matter how many kids you have in the future -it's always there in the back of your mind - If we had more compassionate staff it might be better— not just saying sorry for your loss, a phone call, someone asking how you are doing"

"The staff should give you their time – even though Gynae is a busy ward - you have lost a baby and they should be focused on your emotional needs not just your medical needs"

## Case Study 5 - Simran

"I lost 3 babies - it was just dismissed because they were so early"

"At my 6 week scan - I didn't understand what was happening – there was no interpreter" they didn't try and get someone to translate - it's so important to know what is happening"

"There was no support – I just wanted someone to call/to care" I had no follow up so when I got pregnant again, I didn't know if it would happen again - I became depressed - There should be more information on what happened and if it will affect the next pregnancy"

## Case Study 6 – Hadija

"I lost my baby at 17 weeks - I was scared, the baby was stuck, the feet were dangling, I was shocked, I remember the nurse saying - You have miscarried - Do you understand what I'm saying?"

"I had a retained placenta, it was traumatic, I lost 2 litres of blood"

"One doctor said, 'it's stuck' -it's not an it -it's my baby!"

"One nurse was kind - She encouraged me to have photos and gave me a little teddy"

I think the staff should be educated not to use terms like 'it'

"I would have liked a birth certificate – I have them for my live children, it's like this one isn't acknowledged, like it didn't happen"

# Annex F. Key guidelines

#### **Government Guidelines**

Human Tissues Authority (2015) *Guidance on the disposal of pregnancy remains following pregnancy loss or termination*. Available at <a href="https://www.hta.gov.uk/guidance-professionals/regulated-sectors/post-mortem/guidance-sensitive-handling-pregnancy-remains">https://www.hta.gov.uk/guidance-professionals/regulated-sectors/post-mortem/guidance-sensitive-handling-pregnancy-remains</a>.

#### Coroner

Ministry of Justice. A Guide to Coroner Services for Bereaved People, 2020. Available at:

https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/859076/guide-to-coroner-services-bereaved-people-jan-2020.pdf

Courts and Tribunal Judiciary. Chief Coroner's Guidance No.45 Stillbirth, and Live Birth Following Termination of Pregnancy, 3 February 2023.

https://www.judiciary.uk/guidance-and-resources/chief-coroners-guidance-no-45-stillbirth-and-live-birth-following-termination-of-pregnancy/

#### National Institute for Health and Care Excellence Clinical Guidelines

NICE. Ectopic pregnancy and miscarriage: diagnosis and initial management [NG126]. Published: 17 April 2019; Last updated: 24 November 2021. Available at <a href="https://www.nice.org.uk/guidance/ng126">https://www.nice.org.uk/guidance/ng126</a>.

NICE. *Ectopic pregnancy and miscarriage, Quality standard [QS69]*. Published: 10 September 2014; Last updated November 2021. Available at https://www.nice.org.uk/guidance/qs69.

## **Royal College Clinical Guidelines**

British Association of Perinatal Medicine (2008) The management of babies born extremely preterm at less than 26 weeks of gestation. Available at <a href="https://www.bapm.org/sites/default/files/files/Approved">https://www.bapm.org/sites/default/files/files/Approved</a> manuscript preterm final.pdf

## BAPM ambulance

Royal College of Nursing (2018) *Managing the disposal of pregnancy remains: Guidance for nurses and midwives*. Available at <a href="https://www.rcn.org.uk/professional-development/publications/pub-007321">https://www.rcn.org.uk/professional-development/publications/pub-007321</a>.

Royal College of Obstetricians and Gynaecologists (2016) *Diagnosis and management of ectopic pregnancy (Green-top guideline No. 21)*. Available at <a href="https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg21/">https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg21/</a>. Note, a new draft Recurrent Miscarriage guideline, which supports a move towards a graded model of care, as proposed by experts in The Lancet in April 2021 was published for consultation in October 2021 with the final version expected in 2023.

Royal College of Obstetricians and Gynaecologists (2020) *The management of gestational trophoblastic disease: Green-top guidance No. 38.* Available at <a href="https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg38/">https://www.rcog.org.uk/en/guidelines-research-services/guidelines/gtg38/</a>.

Royal College of Pathologists (2017) *Guidelines on autopsy practice: Fetal autopsy (2nd trimester fetal loss and termination of pregnancy for congenital anomaly).*Available at <a href="https://www.rcpath.org/asset/B20EA503-7799-433C-99160653762F896C/">https://www.rcpath.org/asset/B20EA503-7799-433C-99160653762F896C/</a>

# **National Bereavement Care Pathway Guidelines**

National Bereavement Care Pathway (2020) *Miscarriage, ectopic pregnancy, and molar pregnancy: Full guidance document*. Available at https://nbcpathway.org.uk/professionals/nbcp-pathways-material.

National Bereavement Care Pathway (2020) *Termination of Pregnancy for Fetal Anomaly (TFMR): Full guidance document*. Available at <a href="https://nbcpathway.org.uk/professionals/nbcp-pathways-material">https://nbcpathway.org.uk/professionals/nbcp-pathways-material</a>.

# Other useful guidelines

Institute of Cemetery & Crematorium Management (2015) The Sensitive Disposal of Fetal Remains - Policy and Guidance for Burial and Cremation Authorities and Companies. Available at: <a href="https://www.iccm-uk.com/iccm/foetalremains/">https://www.iccm-uk.com/iccm/foetalremains/</a>.

Johnson J et al. (2020) Consensus Guidelines on the Communication of unexpected news via Ultrasound. Available at:

https://www.bmus.org/static/uploads/resources/ASCKS\_Framework\_guidelines.pdf.and https://journals.sagepub.com/doi/full/10.1177/1742271X20935911.

MBRRACE-UK (2020) Determination of signs of life following spontaneous birth before 24+0 weeks of gestation where, following discussion with the parents, active survival-focused care is not appropriate. Available at: <a href="Home | Signs of life">Home | Signs of life</a> | MBRRACE-UK (le.ac.uk).

Miscarriage Association, Sands and Institute of Cemetery and Crematorium Management (2015) *Guidance for miscarriages that occur at home*. Available at <a href="https://www.miscarriageassociation.org.uk/information/for-health-professionals/guidance-miscarriages-occur-home/">https://www.miscarriageassociation.org.uk/information/for-health-professionals/guidance-miscarriages-occur-home/</a>.

# Annex G. Letters for GP's

# Miscarriage, Ectopic Pregnancy and Molar Pregnancy

Dear (both parents names)

I am sorry to hear of the recent loss of your baby. I am aware this may be a particularly difficult time for you and your partner. I hope that you have already been offered support and advice from the hospital. However, if this is not the case or you wish to discuss your loss further then please do make an appointment to see me. I am also available if you need to discuss any physical health issues you may be experiencing as a result of your loss.

I have enclosed details of support organisations that offer support for parents who have had similar experiences. I hope you find these helpful.

Best Wishes	
Dr	
Ectopic Pregnancy Trust – 020 7733 2653 - www.ectopic.org.uk	

A national organisation offering support and information for those experiencing an ectopic pregnancy.

Saying Goodbye, Part of The Mariposa Trust 0300 323 1350 www.sayinggoodbye.org

Facebook - @sayinggoodbyeuk & Instagram - @Sayinggoodbye charity

An international charity based in the UK offering support to anyone who has lost a baby at any stage of pregnancy, at birth or in infancy, whether the loss was today or decades ago. Support includes 'Saying Goodbye' national remembrance services, social media support, befriending, resources, training for medical professionals and organisations, and campaigning for change in bereavement services and care.

The Miscarriage Association - 01924 200799 - www.miscarriageassociation.org.uk

A national charity offering emotional support via telephone, training and information.

# **Termination of Pregnancy for Medical Reasons**

Dear

I am sorry to hear of the recent loss of your baby. I am aware that this must have been a very difficult and emotional decision for you to make and that this is likely to be a challenging time for you and your partner.

I hope that you have already been offered support and advice from the hospital. However, if this is not the case or you wish to discuss your loss further then please do make an appointment to see me. I am also available if you need to discuss any physical health issues you may be experiencing as a result of your loss.

I have enclosed details of support organisations that offer support for parents who have had similar experiences. I hope you find these helpful.

Best Wishes	
Dr	

# Antenatal Results and Choices (ARC) - 0207 713 7486 - www.arc-uk.org

This charity offers emotional support and information through the process of antenatal screening and the steps that may follow this. There is also a private forum for parents who have lost a baby following a prenatal diagnosis.

Saying Goodbye, Part of The Mariposa Trust 0300 323 1350 www.sayinggoodbye.org

Facebook - @sayinggoodbyeuk & Instagram - @Sayinggoodbye charity

An international charity based in the UK offering support to anyone who has lost a baby at any stage of pregnancy, at birth or in infancy, whether the loss was today or decades ago. Support includes 'Saying Goodbye' national remembrance services, social media support, befriending, resources, training for medical professionals and organisations, and campaigning for change in bereavement services and care.

Cruse Bereavement Support – 0808 8081677 - www.cruse.org.uk

This charity offers bereavement support to anyone who has experienced a loss

#### Stillbirth

Dear (both parents names)

I am sorry to hear of the recent death of your baby. NAME OF CHILD....... I am aware that this is likely to be a very difficult time for you and your partner, which is understandable. I hope that you have already been offered support and advice from the hospital, however, if you do with to discuss anything with me, then please do make an appointment.

We like to see all new mothers at six weeks for a health check and I would be grateful if you could make an appointment with me in due course. The purpose of the appointment is to check your physical and mental health, and an opportunity to discuss any other issues.

I have enclosed details of support organisations that offer support for parents who have had similar experiences. I hope you find these helpful.

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Dr		
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**Saying Goodbye, Part of The Mariposa Trust** - 0300 323 1350

www.sayinggoodbye.org

**Rest Wishes** 

Facebook - @sayinggoodbyeuk & Instagram - @Sayinggoodbye charity

An international charity based in the UK offering support to anyone who has lost a baby at any stage of pregnancy, at birth or in infancy, whether the loss was today or decades ago. Support includes 'Saying Goodbye' national remembrance services, social media support, befriending, resources, training for medical professionals and organisations, and campaigning for change in bereavement services and care.

Stillbirth and Neonatal Death Charity (Sands) - 0808 164 3332 www.sands.org.uk

Sands works to save babies' lives and ensure that, when a baby does die, anyone affected gets the support and care they need. Support is for anyone who has been affected by the death of a baby and wants to talk to someone about their experience.

Twins Trust - 01252 332344 - www.twinstrust.org

This charity supports all parents of multiples who have experienced loss, whether it was during pregnancy, at birth or any point afterwards.

Cruse Bereavement Support – 0808 8081677 - www.cruse.org.uk

This charity offers bereavement support to anyone who has experienced a loss

#### **Neonatal Death**

Dear (both parents names)

I am sorry to hear of the recent death of your child, NAME OF CHILD....... I am aware that this a very difficult time for you and your partner, which is understandable. I hope that you have already been offered support and advice from the hospital, however, if you do with to discuss anything with me then please do make an appointment.

We like to see all new mothers at six weeks for a health check and I would be grateful if you could make an appointment with me in due course. The purpose of the appointment is to check your physical and mental health, and an opportunity to discuss any other issues.

I have enclosed details of support organisations that offer support for parents who have had similar experiences. I hope you find these helpful.

Best Wishes	
Dr	

Stillbirth and Neonatal Death Charity (Sands) - 0808 164 3332 www.sands.org.uk

Sands works to save babies' lives and ensure that, when a baby does die, anyone affected gets the support and care they need. Support is for anyone who has been affected by the death of a baby and wants to talk to someone about their experience.

Saying Goodbye, Part of The Mariposa Trust - 0300 323 1350 www.sayinggoodbye.org

Facebook - @savinggoodbyeuk & Instagram - @Savinggoodbye charity

An international charity based in the UK offering support to anyone who has lost a baby at any stage of pregnancy, at birth or in infancy, whether the loss was today or decades ago. Support includes 'Saying Goodbye' national remembrance services, social media support, befriending, resources, training for medical professionals and organisations, and campaigning for change in bereavement services and care.

Twins Trust Bereavement Service - 01252 332344 - www.twinstrust.org

This charity supports all parents of multiples who have experienced loss, whether it was during pregnancy, at birth or any point afterwards.

The Lullaby Trust – 0808 802 6869 - www.lullabytrust.org.uk

Raising awareness and support for those who have lost a child from SIDS

Child Bereavement UK – 0800 0288840 – www.childbereavementuk.org

Support families when a baby or child of any age dies

Cruse Bereavement Support - 0808 8081677 - www.cruse.org.uk

This charity offers bereavement support to anyone who has experienced a loss

# **Annex H: Support Organisations**

The following is a list of national support organisations and charities working within the field of baby loss support.

Twins Trust Bereavement Service - 01252 332344 - www.twinstrust.org

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Ectopic Pregnancy Trust - 020 7733 2653 - www.ectopic.org.uk

A national organisation offering support and information for those experiencing an ectopic pregnancy.

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The Miscarriage Association - 01924 200799 - www.miscarriageassociation.org.uk

A national charity offering emotional support via telephone, training and information.

**Petals –** 0300 688 0068 – <u>www.petalscharity.org</u>

A charity providing counselling services for people who have received care from specific hospitals

**Tommy's** – 0800 014 7800 – <u>www.tommys.org</u>

A research charity dedicated to finding and treating the causes of loss.

Together for Short Lives – 0117 789 7820 – info@togetherforshortlives.org.uk

Together for Short Lives is a UK charity offering support to the families of children who have life limiting conditions

Abigail's Footsteps - 07534 651156 - www.abigailsfootsteps.co.uk

Providing support, counselling and bereavement training for healthcare professionals as well as resources.

Winston's Wish – 0808 802 0021 – www.winstonswish.org

Winston's Wish provides emotional and practical bereavement support to children, young people and adults supporting them.

Antenatal Results and Choices (ARC) - 0207 713 7486 - www.arc-uk.org

This charity offers emotional support and information through the process of antenatal screening and the steps that may follow this.

CRADLE - 0333 443 4630 - www.cradlecharity.org

A pregnancy loss charity working with healthcare professionals to support pregnancy loss services

4Louis - 0191 5144473 - www.4Louis.co.uk

Providing resources for staff working with families experiencing baby loss

Lily Mae Foundation - 01676 535716 - www.lilymaefoundation.org

Supporting parents by offering emotional support and counselling and training

Child Death Helpline – 0800 282 986 – www.childdeathhelpline.org.uk

A helpline run by bereaved parents to offer support to those who have lost a child.

# Annex I: Letter to accompany 'Certificate of Loss'

Dear...

Firstly, can we say how deeply sorry we are for your loss.

We have both experienced the pain of baby loss and when it is not acknowledged by others and no official recognition is given, it only serves to compound the pain and isolation of the loss.

When the Pregnancy Loss Review was launched in 2018, the introduction of a National Certificate for pre-24-week baby loss was at the top of the agenda, as this had been lobbied for over many years. Our recommendation for the introduction of a 'National Certificate of Loss' being adopted by the Prime Minister in 2022, as part of the Women's Health Strategy, and the news was widely welcomed by bereaved parents across England.

We hope this certificate will support you on your journey through baby loss, and will provide some comfort to you, in the knowledge that you are not alone, and that others are acknowledging your loss too.

Please know that there is much support available, and a list of national support organisations is included with this letter.

Once again, we are so sorry for the loss you have experienced, whether the loss was recent or many years.

Best wishes

**Zoe Clark-Coates MBE** 

Samantha Collinge RM

Samantha Collinge

Co-Chairs of the Pregnancy Loss Review

From Clark- Coates

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# **Glossary**

Antenatal: Before the birth.

**Baby loss:** The loss of a pregnancy at any gestation. In this report, we use the term primarily to refer to losses before 23 completed weeks of gestation.

**Bereavement Lead:** The bereavement lead, is a healthcare professional who has received specialist training in providing care for women (and their partners) experiencing a pregnancy loss. They may be a specialist midwife or nurse, (although this is not always the case). Their role is to coordinate care, provide emotional support to families, and help with practical and statutory requirements such as the bereavement documentation, registration, and funeral arrangements. They are often responsible for staff training, education, and support.

**Bereavement suite or room**: A dedicated room situated away from pregnant women and newborn babies where parents are cared for following pregnancy loss.

**Blighted ovum:** Early pregnancy loss can sometimes be due to a blighted ovum or anembryonic gestation. It happens when a fertilised egg implants in the uterus but the resulting embryo either stops developing early or does not form at all.

**Certification:** Certification is the formal attestation or confirmation of certain characteristics of an object, person, or organisation.

**Cold cot:** A cot, which looks like a conventional Moses basket, is a cooling unit that allows families to spend extra time with their baby, by regulating the baby's temperature. The cot has a thin mattress which is filled with cold water and then connected to a cooling unit, this keeps the mattress constantly cold thus cooling the baby's core temperature.

**Consultant:** A consultant is a lead surgeon or physician of senior rank who has completed specialist training.

**Cremation**: The disposal of a dead person's body by burning it to ashes, typically following a funeral ceremony.

**Ectopic pregnancy:** A pregnancy in which a fertilised egg implants itself outside of the womb, usually in one of the fallopian tubes. Medical or surgical interruption of the pregnancy is commonly required as it may pose a serious health risk to the woman.

**Fetus:** Medical term for a baby before it's born.

**Fetal Movements (FMs):** May be referred to as 'FMs felt' or 'FMF' on medical notes, meaning the fetus has been felt to move.

**Gestation/Gestational Age:** The period inside the uterus(womb) between conception and birth.

**Hospital chaplain:** Hospital chaplains offer spiritual care to patients and their families. They offer prayers and/or a blessing following pregnancy loss and can

support families to organise a funeral. In some hospitals, the chaplain is also the bereavement lead and can help families with practicalities such as registration. Most hospital chaplains can put families in contact with a religious leader of their given faith.

**Intrapartum care:** Professional care provided for a woman during labour and childbirth.

**Intrapartum stillbirth:** Intrapartum stillbirth is the term for when a stillbirth occurs after labour has begun.

# Management options for an early baby loss:

- Expectant management allowing the miscarriage to happen naturally. This can sometimes take two or three weeks and women may be invited for a scan to confirm the womb is empty or given a pregnancy test to do at home and asked not to return if the test is negative.
- Medical management taking medication (pills and/or vaginal pessaries) to start
  or speed up the process of a miscarriage. The exact form of treatment will
  depend on a woman's circumstances and may be done as an out-patient or inpatient on a gynaecology ward or, if one is not available, on a mixed acute care
  ward.
- <u>Surgical management</u> an operation to remove pregnancy tissue. Depending on a woman's circumstances, surgery may be done under general or local anaesthetic in a hospital ward, a day surgery unit or an out-patient clinic.

**Maternity Team Care:** Although every woman following booking will have care provided by a midwife, women with complex pregnancies, will have care provided by a maternity team comprising midwives, obstetricians, anaesthetists, neonatologists, and other specialists working in partnership.

**Midwife:** A skilled health care professional who works in partnership with women and their families to give support, care and advice during pregnancy, labour, and the postnatal period.

**Midwifery care:** Care where the midwife is the lead professional.

**Miscarriage:** The loss of a pregnancy before the first 23 completed weeks of gestation.

**Missed miscarriage:** A missed miscarriage, also called a silent miscarriage, is where the baby has died or not developed but has not been physically miscarried. In many cases, there has been no sign that anything was wrong, however at some point, usually during an ultrasound scan it becomes clear that the baby has died.

**Molar pregnancy:** Molar pregnancy is an abnormal form of pregnancy (gestational trophoblastic disease) in which a non-viable fertilized egg implants in the uterus and develops into a mass in the uterus.

**Mortuary:** The hospital mortuary is the part of the hospital where bodies are kept after death.

**Mortuary technician:** A mortuary technician is a person who cares for bodies in the mortuary. They work closely with funeral directors, the coroner, and the pathologist.

Neonate: A newborn infant less than 28 days of age.

**Neonatologist:** A neonatologist specialises in the care of newborn babies and often works in neonatal intensive care units (NICUs).

Neonatal care: Clinical care for newborn babies under 28 days of age.

**Neonatal death**: Death of a live born baby before 28 completed days from the time of birth.

**Neonatal unit:** A unit within a hospital providing specialist care at varying levels (special, high dependency or intensive care) for premature or ill babies under 28 days of age.

NHS trust: A National Health Service trust is an organisation within the English NHS, generally serving either a geographical area or a specialised function (such as an ambulance service). In any particular location, there may be several trusts involved in the different aspects of healthcare for a resident. There are several types of NHS Trusts, including NHS Hospital Trusts (also known as an acute trusts), which provide secondary care services; NHS Mental Health Trusts; NHS Ambulance Services Trusts; Community Health NHS Trusts.

**Obstetrician:** A doctor who has had specialist training in the care of women during pregnancy and childbirth.

**Obstetrics and Gynaecology:** Obstetrics and Gynaecology is the medical specialty that encompasses the two subspecialties of obstetrics (pregnancy, childbirth, and the post-partum period) and gynaecology (the health of the female reproductive system).

**Pathologist:** A pathologist is a doctor who diagnoses disease and sometimes the cause of death by examining cells and tissue samples and carrying out a postmortem.

**Perinatal Death:** A perinatal death is a fetal death (stillbirth) or an early neonatal death during the perinatal period (the period immediately before and after birth).

**Placenta or Afterbirth:** A temporary organ that connects the developing fetus via the umbilical cord to the uterine wall to allow nutrient uptake, thermoregulation, waste elimination and gaseous exchange via the mother's blood supply. It also produces hormones to support the pregnancy.

**Post-traumatic stress disorder (PTSD):** a type of anxiety disorder which tends to develop after a person has been exposed to a very frightening or distressing event.

**Postnatal care:** Professional care provided to meet the needs of women and their babies up to 6 -8 weeks after birth.

**Postnatal period:** The 6 to 8-week period following birth.

**Postpartum:** Relating to the period of a few days up to a few weeks after the birth.

**Preterm:** Also known as premature, an infant with a gestational age of less than 37 completed weeks.

**Products of conception**: A clinical term used to refer to pregnancy remains or a fetus that is delivered from a woman's body following a loss.

**Registration**: In England and Wales, registration is the process by which all cases of a life event (birth, death, marriage or civil partnership, stillbirth) are recorded in an official register and formally reported to the General Registrar Office (GRO). Once registered, a registrar can then issue a certificate to parents/family members. Stillbirth registration is currently a mandatory process and must be reported within a certain timeframe (usually 42 days).

**Signs of life:** Signs shown by a baby when it is delivered that demonstrate it has been born alive. These can include spontaneous heartbeat, crying and active body movement.

**Sonographer:** A sonographer is a specialist practitioner who is trained to carry out ultrasound examinations. Midwife ultra-sonographers are midwives with a specialist post graduate qualification in ultra-sonography.

**Stillbirth:** A baby delivered without signs of life and is known to have died after 24 weeks of pregnancy.

**Term:** Used to describe the period of time at the end of a pregnancy when a baby might be expected to be born. The normal duration of a human pregnancy is 37-42 weeks.

**Termination of pregnancy for medical reasons (TPMR)**: The interruption of a pregnancy by either medical management (i.e., taking medication to end the pregnancy) or surgical management (i.e., a procedure to surgically remove the fetus/baby). A decision may be made by parents to terminate a pregnancy if tests identify that the baby has a life-threatening or life-altering condition or if pregnancy complications pose a significant threat to the life of the mother or baby.

**Trimester:** One third of a pregnancy's usually expected term (approximately 12 weeks).

**Ultrasound scan:** A screening or diagnostic technique in which very high frequency sound waves are passed into the body, and the reflected echoes are detected and analysed to build a picture of the internal organs or of a fetus/baby in the uterus.

**Umbilical cord:** The thick cord of intertwining blood vessels that links baby and placenta and carries oxygen and nourishment to the baby whilst in the uterus.

**Uterus or Womb:** The hollow muscular organ in which the fetus develops until birth

# References

- <sup>6</sup> MBRRACE-UK. National clinical guidance for the determination of signs of life following spontaneous birth before 24+0 weeks of gestation where, following discussion with the parents, active survival-focused care is not appropriate. November 2020. <a href="https://timms.le.ac.uk/signs-of-life/resources/signs-of-life-guidance-v1.2.pdf">https://timms.le.ac.uk/signs-of-life/resources/signs-of-life-guidance-v1.2.pdf</a>.
- <sup>7</sup> Johnson J, Arezina J, Tomlin L, et al. UK consensus guidelines for the delivery of unexpected news in obstetric ultrasound: The ASCKS framework. Ultrasound. 2020;28(4):235-245. doi:10.1177/1742271X20935911.
- <sup>8</sup> Law Commission of England and Wales, Law Commission No 411, Scottish Law Commission, Scottish Law Commission No. 262, Building families through surrogacy: a new law. Volume II: Full Report, 28 March 2023 https://www.scotlawcom.gov.uk/files/9416/8001/1648/2. Surrogacy full report.pdf.
- <sup>9</sup> Association of Chaplaincy in General Practice. Improving care through listening and guidance. GP Chaplaincy Handbook A practical guide to service provision. 2019 (Revised June 2022). <a href="http://acgp.co.uk/wp-content/uploads/2022/10/2019-ACGP-Handbook\_Revised-Jun-2022.pdf">http://acgp.co.uk/wp-content/uploads/2022/10/2019-ACGP-Handbook\_Revised-Jun-2022.pdf</a>.
- <sup>10</sup> Association of Chaplaincy in General Practice. Essential values and principles for Chaplaincy in General Practice. <a href="http://acgp.co.uk/wp-content/uploads/2021/11/Essential-values-and-principles-for-Chaplaincy-in-General-Practice.pdf">http://acgp.co.uk/wp-content/uploads/2021/11/Essential-values-and-principles-for-Chaplaincy-in-General-Practice.pdf</a>.
- <sup>11</sup> Association of Chaplaincy in General Practice. Spiritual Care Competences Framework for Primary Care Chaplains. <a href="http://acgp.co.uk/wp-content/uploads/2021/11/Spiritual-Care-Competences-Framework-for-Primary-Care-Chaplains.pdf">http://acgp.co.uk/wp-content/uploads/2021/11/Spiritual-Care-Competences-Framework-for-Primary-Care-Chaplains.pdf</a>.
- <sup>12</sup> The National Maternity Review. *Better Births Improving outcomes of maternity services in England A five rear forward view for maternity care*. <a href="https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf">https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf</a>.
- <sup>13</sup> Department of Health and Social Care. Safer maternity care: progress and next steps A review on the implementation of the national maternity safety strategy's safer maternity care action plan. Published 28 November 2017.
- https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/662969/Safer\_maternity\_care\_- progress\_and\_next\_steps.pdf.
- <sup>14</sup> All Party Parliamentary Group for Baby Loss. Beyond Awareness to Action: Tackling baby loss in the UK, October2016. <a href="https://www.lullabytrust.org.uk/wp-content/uploads/APPG-on-baby-loss-Beyond-Awareness-to-Action-Tackling-baby-loss-in-the-UK-1.pdf">https://www.lullabytrust.org.uk/wp-content/uploads/APPG-on-baby-loss-Beyond-Awareness-to-Action-Tackling-baby-loss-in-the-UK-1.pdf</a>.
- <sup>15</sup> NHS England. *New dedicated mental health services for new expectant and bereaved mums.* https://www.england.nhs.uk/2021/04/dedicated-mh-services/.
- <sup>16</sup> The Lancet. *Miscarriage Matters* (2021). <a href="https://www.thelancet.com/series/miscarriage">https://www.thelancet.com/series/miscarriage</a>.
- <sup>17</sup> NHS England. Equity and equality: Guidance for local maternity systems. September 2021. https://www.england.nhs.uk/wp-content/uploads/2021/09/C0734-equity-and-equality-guidance-for-local-maternity-systems.pdf.
- <sup>18</sup> Department of Health and Social Care. Voluntary, community and social enterprise (VCSE) Health and Wellbeing Fund 2022 to 2025: women's reproductive wellbeing in the workplace. May 2022. https://www.gov.uk/government/publications/vcse-health-and-wellbeing-fund-2022-to-2025-womens-reproductive-wellbeing-in-the-workplace#:~:text=Guidance-
- ,VCSE%20Health%20and%20Wellbeing%20Fund%202022%20to%20205%3A%20women%27s%20reproductive.reproductive%20wellbeing%20in%20the%20workplace .

<sup>&</sup>lt;sup>1</sup> Civil Partnerships, Marriages, and Deaths (Registration etc) Act, 2019. https://bills.parliament.uk/bills/2063.

<sup>&</sup>lt;sup>2</sup> Memtsa M, Goodhart V, Ambler G, Brocklehurst P, Keeney E, Silverio S, et al. Variations in the organisation of and outcomes from Early Pregnancy Assessment Units: the VESPA mixed-methods study. Health Serv Deliv Res 2020;8(46).

<sup>&</sup>lt;sup>3</sup> British Association of Perinatal Medicine. Perinatal Management of Extreme Preterm Birth - A Framework for Practice (2019), October 2019. <a href="https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019">https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019</a>.

<sup>&</sup>lt;sup>4</sup> British Association of Perinatal Medicine. Pre-hospital management of the baby born at extreme preterm gestation, A BAPM Framework for Practice (2022), February 2022. <a href="https://www.bapm.org/resources/pre-hospital-management-of-the-baby-born-at-extreme-preterm-gestation">https://www.bapm.org/resources/pre-hospital-management-of-the-baby-born-at-extreme-preterm-gestation</a>.

<sup>&</sup>lt;sup>5</sup> Together for Short Lives. A Perinatal Pathway for Babies with Palliative Care Needs. Second edition 2017. https://www.togetherforshortlives.org.uk/app/uploads/2019/04/ProRes-Perinatal-Pathway-for-Babies-with-Palliative-Care-Needs-Reprint-2019.pdf.

- <sup>19</sup> Department of Health and Social Care. *Our Vision for the Women's Health Strategy for England*. London: Department of Health and Social Care; 2021.
- https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/1042631/dhsc-our-vision-for-the-women s-health-strategy-for-england.pdf.
- <sup>20</sup> Office for National Statistics. Birth characteristics in England and Wales: 2021. Release date: 19 January 2023.
- https://www.ons.gov.uk/file?uri=/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/bir thcharacteristicsinenglandandwales/2021/birthcharacteristics2021workbookfinal.xlsx.
- <sup>21</sup> Malone F.D., D'alton M.E. Multiple Gestation : Clinical Characteristics and Management in Creasy and Resnik's Maternal-Fetal Medicine: Principles and Practice Eighth Edition (2019), 40, 654-675.e5.
- <sup>22</sup> Morris RK, Mackie F, Garces AT, Knight M, Kilby MD (2020) The incidence, maternal, fetal and neonatal consequences of single intrauterine fetal death in monochorionic twins: A prospective observational UKOSS study. PLoS ONE 15(9):e0239477. <a href="https://doi.org/10.1371/journal.pone.0239477">https://doi.org/10.1371/journal.pone.0239477</a>.
- <sup>23</sup> Royal College of Obstetricians and Gynaecologists. Ectopic Pregnancy. <a href="https://www.rcog.org.uk/for-the-public/browse-all-patient-information-leaflets/ectopic-pregnancy-patient-information-leaflet/">https://www.rcog.org.uk/for-the-public/browse-all-patient-information-leaflets/ectopic-pregnancy-patient-information-leaflet/</a>.
- <sup>24</sup> National Institute for Health and Care Excellence (NICE). Ectopic pregnancy and miscarriage: diagnosis and initial management [NG126]. London:NICE;2019, updated November 2021.
- <sup>25</sup> The Ectopic Pregnancy Trust. What is an ectopic pregnancy. <a href="https://ectopic.org.uk/what-is-an-ectopic-pregnancy#:~:text=Ectopic%20pregnancy%20is%20a%20common,of%20the%20uterus%20(womb)">https://ectopic.org.uk/what-is-an-ectopic-pregnancy#:~:text=Ectopic%20pregnancy%20is%20a%20common,of%20the%20uterus%20(womb)</a>.
- <sup>26</sup> Quenby S, Ioannis D Gallos I D, Dhillon-Smith RK. Miscarriage matters: the epidemiological, physical, psychological, and economic costs of early pregnancy loss. *Lancet* 2021; **397**: 1658–67.
- <sup>27</sup> Agampodi S, Hettiarachchi A, Agampodi T. Making miscarriage matter. Lancet 2021; 398: 745.
- <sup>28</sup> Austin L, Littlemore J, McGuinness S, Turner S, Fuller D, Kuberska K. Effective Communication Following Pregnancy Loss: A Study in England. Camb Q Healthc Ethics. 2021 Jan;30(1):175-187. doi: 10.1017/S0963180120000651. PMID: 33371918.
- <sup>29</sup> NHS. Molar Pregnancy. <a href="https://www.nhs.uk/conditions/molar-pregnancy/">https://www.nhs.uk/conditions/molar-pregnancy/</a>.
- <sup>30</sup> Draper ES, Gallimore ID, Smith LK, Matthews RJ, Fenton AC, Kurinczuk JJ, Smith PW, Manktelow BN, on behalf of the MBRRACE-UK Collaboration. MBRRACE-UK Perinatal Mortality Surveillance Report, UK Perinatal Deaths for Births from January to December 2020. Leicester: The Infant Mortality and Morbidity Studies, Department of Health Sciences, University of Leicester. 2022.
- <sup>31</sup> Quenby S, Ioannis D Gallos I D, Dhillon-Smith RK. Miscarriage matters: the epidemiological, physical, psychological, and economic costs of early pregnancy loss. *Lancet* 2021; **397**: 1658–67.
- <sup>32</sup> Peter M and Wheeler R. The Black Maternity Experiences Survey A Nationwide Study of Black Women's Experiences of Maternity Services in the United Kingdom, May 2022. https://www.fivexmore.com/blackmereport.
- <sup>33</sup> International Classification of Diseases, 10<sup>th</sup> Revision.
- 34 NHS, Maternity Services Data Set Overview. https://v3.datadictionary.nhs.uk/data\_dictionary/messages/clinical\_data\_sets/data\_sets/maternity\_services\_data\_set\_fr.asp?shownav=1#:~:text=The%20Maternity%20Services%20Data%20Set%20%28MSDS%29%20is%20a, with%20baby%E2%80%99s%20demographics%2C%20admissions%2C%20diagnoses%20and%20Screening%20Tests.
- <sup>35</sup> Department for Education. Relationships Education, Relationships and Sex Education (RSE) and Health Education, Statutory guidance for governing bodies, proprietors, head teachers, principals, senior leadership teams, teachers. <a href="https://www.gov.uk/government/publications/relationships-education-relationships-and-sex-education-rse-and-health-education">https://www.gov.uk/government/publications/relationships-education-relationships-and-sex-education-rse-and-health-education.</a>
- <sup>36</sup> Bigrigg MA, Read MD. Management of women referred to early pregnancy assessment unit: care and cost effectiveness. Br Med J. 1991;302(6776):577–9.
- <sup>37</sup> Bigrigg MA, Read MD. Management of women referred to early pregnancy assessment unit: care and cost effectiveness. Br Med J. 1991;302(6776):577–9.
- <sup>38</sup> NICE. Ectopic pregnancy and miscarriage: diagnosis and initial management [NG126]. Published: 17 April 2019; Last updated: 24 November 2021. Available at <a href="https://www.nice.org.uk/guidance/ng126">https://www.nice.org.uk/guidance/ng126</a>.
- <sup>39</sup> NHS England. 2022/23 National Tariff Payment System. 31 March 2022. https://www.england.nhs.uk/wp-content/uploads/2020/11/22-23-National-tariff-payment-system.pdf.
- <sup>40</sup> NICE. Ectopic pregnancy and miscarriage: diagnosis and initial management [NG126]. Published: 17 April 2019; Last updated: 24 November 2021. Available at <a href="https://www.nice.org.uk/guidance/ng126">https://www.nice.org.uk/guidance/ng126</a>.
- <sup>41</sup> Memtsa M, Goodhart V, Ambler G, Brocklehurst P, Keeney E, Silverio S, et al. Variations in the organisation of and outcomes from Early Pregnancy Assessment Units: the VESPA mixed-methods study. Health Serv Deliv Res 2020;8(46).

- <sup>42</sup> Cox, R., Khalid, S., Brierly, G. *et al.* Implementing a community model of early pregnancy care. *BMC Health Serv Res* **20**, 664 (2020). https://doi.org/10.1186/s12913-020-05524-8.
- <sup>43</sup> Memtsa M, Goodhart V, Ambler G, Brocklehurst P, Keeney E, Silverio S, et al. Variations in the organisation of and outcomes from Early Pregnancy Assessment Units: the VESPA mixed-methods study. Health Serv Deliv Res 2020;8(46).
- <sup>44</sup> WF Baile, R Buckman, R Lenzi, G Glober, EA Beale and AP Kudelka (2002) *SPIKES—A six-step protocol for delivering bad news: application to the patient with cancer. The Oncologist* 5:302-311.
- <sup>45</sup> Johnson, J. 2018. Six Ways that Breaking Bad and Difficult News in Ultrasound is Different to Other Settings. https://judithjohnsonphd.com/2018/09/26/breaking-bad-news-ultrasound/.
- <sup>46</sup> Johnson J, Arezina J, Tomlin L, et al. UK consensus guidelines for the delivery of unexpected news in obstetric ultrasound: The ASCKS framework. *Ultrasound* 2020; 28(4) 235-245.
- <sup>47</sup> British Medical Ultrasound Society. Consensus Guidelines on the Communication of Unexpected News Via Ultrasound (2020). https://www.bmus.org/static/uploads/resources/ASCKS\_Framework\_guidelines.pdf.
- <sup>48</sup> Society of Radiographers and British Medical Ultrasound Society. Guidelines for Professional Ultrasound Practice, Revision 7, December 2022.
- https://www.sor.org/learning-advice/professional-body-guidance-and-publications/documents-and-publications/policy-guidance-document-library/sor-and-bmus-guidelines-seventh-edition.
- <sup>49</sup> NHS Employers. Sonographers, sonography and the regulation of the medical ultrasound workforce (February 2022). <a href="https://www.nhsemployers.org/articles/sonographers-sonography-and-regulation-medical-ultrasound-workforce">https://www.nhsemployers.org/articles/sonographers-sonography-and-regulation-medical-ultrasound-workforce</a>.
- <sup>50</sup> Care Quality Commission. Choosing a baby scanning service, November 2022. <a href="https://www.cqc.org.uk/care-services/help-choosing-care/choosing-baby-scanning-service">https://www.cqc.org.uk/care-services/help-choosing-care/choosing-baby-scanning-service</a>.
- <sup>51</sup> The Royal College of Radiologists, the Society and College of Radiographers. Standards for the provision of an ultrasound service. London: The Royal College of Radiologists, 2014. <a href="https://www.rcr.ac.uk/system/files/publication/field\_publication\_files/BFCR%2814%2917\_Standards\_ultrasound.pdf">https://www.rcr.ac.uk/system/files/publication/field\_publication\_files/BFCR%2814%2917\_Standards\_ultrasound.pdf</a>.
- <sup>52</sup> The Society and College of Radiographers. Competencies for ultrasound practice in private baby scan clinics. October 2022. <a href="https://www.sor.org/getmedia/48ae28b7-dcc7-4c95-8bb9-fc04012ef983/Competencies-for-ultrasound-practice-in-private-baby-scan-clinics-v1-3-FINAL">https://www.sor.org/getmedia/48ae28b7-dcc7-4c95-8bb9-fc04012ef983/Competencies-for-ultrasound-practice-in-private-baby-scan-clinics-v1-3-FINAL</a>.
- <sup>53</sup> Department of Health and Social Care. Regulating healthcare professionals, protecting the public. 24 March 2021 <a href="https://www.gov.uk/government/consultations/regulating-healthcare-professionals-protecting-the-public">https://www.gov.uk/government/consultations/regulating-healthcare-professionals-protecting-the-public</a>.
- Department of Health and Social Care. Consultation outcome- Regulating healthcare professionals, protecting the public: consultation response executive summary. Updated 17 February 2023. Regulating healthcare professionals, protecting the public: consultation response executive summary GOV.UK (www.gov.uk).
- <sup>55</sup> Office for Health Improvement and Disparities. *Language interpreting and translation: migrant health guide. Advice and guidance on the health needs of migrant patients for healthcare practitioners* (Last updated 22 March 2021). https://www.gov.uk/guidance/language-interpretation-migrant-health-guide.
- <sup>56</sup> Royal College of Obstetricians and Gynaecologists. Early Miscarriage Patient Information Leaflet. https://www.rcog.org.uk/for-the-public/browse-all-patient-information-leaflets/early-miscarriage-patient-information-leaflet/.
- <sup>57</sup> NICE. Ectopic pregnancy and miscarriage: diagnosis and initial management [NG126]. Published: 17 April 2019; Last updated: 24 November 2021. Available at https://www.nice.org.uk/guidance/ng126.
- <sup>58</sup> Twins Trust. Bereavement Support Booklet, . <a href="https://twinstrust.org/static/1a37eb18-be5d-4b6b-83ee8af6bf19bf45/4eeec816-bb98-4f32-a2de3b784454c0f4/bereavement-booklet.pdf">https://twinstrust.org/static/1a37eb18-be5d-4b6b-83ee8af6bf19bf45/4eeec816-bb98-4f32-a2de3b784454c0f4/bereavement-booklet.pdf</a>.
- <sup>59</sup> Newcastle Neonatal Research Group. The Butterfly Project. <a href="https://www.neonatalresearch.net/butterfly-project.html">https://www.neonatalresearch.net/butterfly-project.html</a>.
- 60 Human Tissue Act, 2004. https://www.legislation.gov.uk/ukpga/2004/30/contents.
- <sup>61</sup> Human Tissue Authority. Guidance on the disposal of pregnancy remains following pregnancy loss or termination, March 2015. <a href="https://www.hta.gov.uk/guidance-professionals/regulated-sectors/post-mortem/guidance-sensitive-handling-pregnancy-0">https://www.hta.gov.uk/guidance-professionals/regulated-sectors/post-mortem/guidance-sensitive-handling-pregnancy-0</a>.
- <sup>62</sup> Royal College of Nursing. Managing the Disposal of Pregnancy Remains, RCN guidance for nursing and midwifery practice. Updated 2021. https://www.rcn.org.uk/Professional-Development/publications/pub-007321.
- <sup>63</sup> Smith L, et al. Comparing regional infant death rates: the influence of preterm births <24 weeks of gestation Arch Dis Child Fetal Neonatal Ed 2013;98:F103–F107. doi:10.1136/fetalneonatal-2011-301359.

- <sup>64</sup> Joseph K S, Liu S, Rouleau J, Lisonkova S, Hutcheon J A, Sauve R et al. Influence of definition based versus pragmatic birth registration on international comparisons of perinatal and infant mortality: population based retrospective study BMJ 2012; 344 :e746 doi:10.1136/bmj.e746.
- <sup>65</sup>Gov.UK, Statutory Parental Bereavement Pay and Leave. <a href="https://www.gov.uk/parental-bereavement-pay-leave/check-if-youre-eligible">https://www.gov.uk/parental-bereavement-pay-leave/check-if-youre-eligible</a>.
- 66 Still-Birth (Definition) Act 1992. https://www.legislation.gov.uk/ukpga/1992/29.
- <sup>67</sup> British Association of Perinatal Medicine. Perinatal management of extreme preterm birth before 27 weeks of gestation: A Framework for Practice: British Association of Perinatal Medicine, October 2019. <a href="https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019">https://www.bapm.org/resources/80-perinatal-management-of-extreme-preterm-birth-before-27-weeks-of-gestation-2019</a>.
- <sup>68</sup> British Association of Perinatal Medicine. Pre-hospital management of the baby born at extreme preterm gestation, February 2022. <a href="https://www.bapm.org/resources/pre-hospital-management-of-the-baby-born-at-extreme-preterm-gestation">https://www.bapm.org/resources/pre-hospital-management-of-the-baby-born-at-extreme-preterm-gestation</a>.
- <sup>69</sup> Draper ES, Gallimore ID, Smith LK, Matthews RJ, Fenton AC, Kurinczuk JJ, Smith PW, Manktelow BN, on behalf of the MBRRACE-UK Collaboration. MBRRACE-UK Perinatal Mortality Surveillance Report, UK Perinatal Deaths for Births from January to December 2020. Leicester: The Infant Mortality and Morbidity Studies, Department of Health Sciences, University of Leicester. 2022.
- <sup>70</sup> MBRRACE-UK. National clinical guidance for the determination of signs of life following spontaneous birth before 24+0 weeks of gestation where, following discussion with the parents, active survival-focused care is not appropriate. November 2020. https://timms.le.ac.uk/signs-of-life/resources/signs-of-life-guidance-v1.2.pdf.
- <sup>71</sup> Together for Short Lives. Perinatal Pathway for Babies with Palliative Care Needs. https://www.togetherforshortlives.org.uk/resource/perinatal-pathway-babies-palliative-care-needs/.
- <sup>72</sup> National Institute for Health and Care Excellence. End of life care for infants, children and young people with life-limiting conditions: planning and management [NG61], Published: 07 December 2016 Last updated: 25 July 2019. <a href="https://www.nice.org.uk/guidance/ng61">https://www.nice.org.uk/guidance/ng61</a>.
- <sup>73</sup> Courts and Tribunal Judiciary. Chief Coroner's Guidance No.45 Stillbirth, and Live Birth Following Termination of Pregnancy, February 2023. <u>Chief Coroner's Guidance No.45 Stillbirth, and Live Birth Following Termination of Pregnancy Courts and Tribunals Judiciary.</u>
- <sup>74</sup> The Free Dictionary. Bereavement care. <a href="https://medical-dictionary.thefreedictionary.com/bereavement+care">https://medical-dictionary.thefreedictionary.com/bereavement+care</a>.
- <sup>75</sup> Welsh Government. National framework for the delivery of bereavement care. 2021. https://gov.wales/national-framework-delivery-bereavement-care-html.
- <sup>76</sup> NHS England. Perinatal Post-mortem Consent. <a href="https://www.e-lfh.org.uk/programmes/perinatal-post-mortem-consent/">https://www.e-lfh.org.uk/programmes/perinatal-post-mortem-consent/</a>.
- <sup>77</sup> Nynas J, Narang P, Kolikonda MK, Lippmann S. Depression and Anxiety Following Early Pregnancy Loss: Recommendations for Primary Care Providers. Prim Care Companion CNS Disord. 2015;17(1):10.4088/PCC.14r01721. Published 2015 Jan 29. doi:10.4088/PCC.14r01721.
- <sup>78</sup> San Lazaro Campillo I, Meaney S, McNamara K, et al. Psychological and support interventions to reduce levels of stress, anxiety or depression on women's subsequent pregnancy with a history of miscarriage: an empty systematic reviewBMJ Open 2017;7:e017802. doi: 10.1136/bmjopen-2017-017802.
- <sup>79</sup> Quenby S, Ioannis D Gallos I D, Dhillon-Smith RK. Miscarriage matters: the epidemiological, physical, psychological, and economic costs of early pregnancy loss. Lancet 2021; 397: 1658–67.
- <sup>80</sup> Farren J, Jalmbrant M, Falconieri N, Mitchell-Jones N, Bobdiwala S, Al-Memar M, Tapp S, Van Calster B, Wynants L, Timmerman D, Bourne T. Posttraumatic stress, anxiety and depression following miscarriage and ectopic pregnancy: a multicenter, prospective, cohort study. Am J Obstet Gynecol. 2020 Apr;222(4):367.e1-367.e22. doi: 10.1016/j.ajog.2019.10.102. Epub 2019 Dec 13. PMID: 31953115.
- <sup>81</sup> Farren J, Jalmbrant M, Falconieri N, et al. Posttraumatic stress, anxiety and depression following miscarriage and ectopic pregnancy: a multicentre, prospective, cohort study. AJOG 2019; 2222(4):E1-367.E22 DOI:https://doi.org/10.1016/j.ajog.2019.10.102.
- <sup>82</sup> National Institute for Health and Care Excellence. Clinical Knowledge Summary Miscarriage. Last revised November 2020. <a href="https://cks.nice.org.uk/topics/miscarriage/">https://cks.nice.org.uk/topics/miscarriage/</a>.
- 83 Mariposa Trust Survey, August 2017.
- <sup>84</sup> Farren J, Mitchell-Jones N, Verbakel JY, Timmerman D, Jalmbrant M, Bourne T. The psychological impact of early pregnancy loss. Hum Reprod Update. 2018 Nov 1;24(6):731-749. doi: 10.1093/humupd/dmy025. PMID: 30204882.
- <sup>85</sup> Farren J, Jalmbrant M, Ameye L, et al. Post-traumatic stress, anxiety and depression following miscarriage or ectopic pregnancy: a prospective cohort study. *BMJ Open* 2016;6:e011864. doi:10.1136/bmjopen-2016-011864

- <sup>86</sup> Baby Loss Awareness Alliance. Out of Sight, Out of Mind Bereaved parents falling through the gaps in mental health care'. 2019 Baby Loss Awareness Week Report. <a href="https://babyloss-awareness.org/wp-content/uploads/2019/10/BLAW-Out-of-Sight-Out-of-Mind-Report-2019.pdf">https://babyloss-awareness.org/wp-content/uploads/2019/10/BLAW-Out-of-Sight-Out-of-Mind-Report-2019.pdf</a>.
- <sup>87</sup> See also p. 36-37 of the NBCP for 'Miscarriage, ectopic pregnancy and molar pregnancy (Full guidance document)' for guidance for healthcare professionals on providing emotional and mental health support for pre-24 weeks pregnancy loss.
- <sup>88</sup> NICE (2014) Antenatal and postnatal mental health: clinical management and service guidance (CG192). Last updated February 2020. https://www.nice.org.uk/guidance/cg192.
- <sup>89</sup> Weng SC, Chang JC, Yeh MK, Wang SM, Lee CS, Chen YH. Do stillbirth, miscarriage, and termination of pregnancy increase risks of attempted and completed suicide within a year? A population-based nested case-control study. BJOG. 2018 Jul;125(8):983-990. doi: 10.1111/1471-0528.15105.
- 90 Mariposa Trust Survey. Suicide and Mental Health Resulting from Baby Loss. October 2018.
- <sup>91</sup> Farren J, Jalmbrant M, Falconieri N, et al. Differences in post-traumatic stress, anxiety and depression following miscarriage or ectopic pregnancy between women and their partners: multi-centre prospective cohort study. Ultrasound Obstet Gynecol2021;57: 141 148. DOI:10.1002/uoq.23147.
- <sup>92</sup> Online survey circulated through the Bereavement Midwives Forum in August-September 2018. 92% of respondents are based in an NHS Trust, 90% are based in England and 82% identified as specialist bereavement midwives. Total of 39 responses. Respondents are unlikely to be fully representative.
- <sup>93</sup> Due, C., Chiarolli, S. and Riggs, D. (2017). The impact of pregnancy loss on men's health and wellbeing: a systematic review. BMC Pregnancy and Childbirth, 17(1).
- 94 NHS. The NHS long term plan. 2019. https://www.longtermplan.nhs.uk/.
- <sup>95</sup> National Institute of Health Research. 22/82 Improving mental health outcomes for women and partners who have experienced pregnancy not ending in live births. Version 1.0, published 28 June 2022. https://www.nihr.ac.uk/documents/2282-improving-mental-health-outcomes-for-women-and-partners-who-have-experienced-pregnancy-not-ending-in-live-births/30853#research-question.
- <sup>96</sup> Nynas J, Narang P, Kolikonda MK, Lippmann S. Depression and Anxiety Following Early Pregnancy Loss: Recommendations for Primary Care Providers. Prim Care Companion CNS Disord. 2015 Jan 29;17(1):10.4088/PCC.14r01721. doi: 10.4088/PCC.14r01721. PMID: 26137360; PMCID: PMC4468887.
- <sup>97</sup> A. Coomarasamy, A.J. Devall, V. Cheed, et al. A randomized trial of progesterone in women with bleeding in early pregnancy. N. Engl. J. Med, 380 (19) (2019), pp. 1815-1824.
- <sup>98</sup> Devall AJ, Papadopoulou A, Podesek M, Haas DM, Price MJ, Coomarasamy A, Gallos ID. Progestogens for preventing miscarriage: a network meta-analysis. Cochrane Database of Systematic Reviews 2021, Issue 4. Art. No.: CD013792. DOI: 10.1002/14651858.CD013792.pub2.
- <sup>99</sup> NICE. Ectopic pregnancy and miscarriage: diagnosis and initial management [NG126]. Published: 17 April 2019; Last updated: 24 November 2021. Available at <a href="https://www.nice.org.uk/guidance/ng126">https://www.nice.org.uk/guidance/ng126</a>.
- <sup>100</sup> Royal College of Nursing. Clinical Nurse Specialist in Early Pregnancy Care, 2021. <a href="https://www.rcn.org.uk/-/media/Royal-College-Of-Nursing/Documents/Publications/2023/January/010-625.pdf">https://www.rcn.org.uk/-/media/Royal-College-Of-Nursing/Documents/Publications/2023/January/010-625.pdf</a>.
- <sup>101</sup> Royal College of Nursing. Clinical Nurse Specialists in Early Pregnancy Care Standards Consensus Statement, 2023. <a href="https://www.rcn.org.uk/-/media/Royal-College-Of-Nursing/Documents/Publications/2023/January/010-625.pdf">https://www.rcn.org.uk/-/media/Royal-College-Of-Nursing/Documents/Publications/2023/January/010-625.pdf</a>.
- <sup>102</sup> Independent Maternity Review. (2022). Ockenden report Final: Findings, conclusions, and essential actions from the independent review of maternity services at the Shrewsbury and Telford Hospital NHS Trust (HC 1219). Crown.
- https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\_data/file/1064302/Final-Ockenden-Report-web-accessible.pdf.
- <sup>103</sup> Sands. Briefing on Access to bereavement care training for healthcare professionals across the UK. June 2022. https://sands.org.uk/sites/default/files/Bereavement%20Care%20Training%20Report%202022.pdf
- <sup>104</sup> Johnson, J., Arezina, J., McGuinness, A., Culpan, A. and Hall, L. (2018). Breaking bad and difficult news in obstetric ultrasound and sonographer burnout: Is training helpful?. Ultrasound, 27(1), pp.55-63.
- <sup>105</sup> NHS Staff Survey 2022 National results briefing. <u>NHS Staff Survey 2022 National results briefing (nhsstaffsurveys.com).</u>
- <sup>106</sup> Nash M, Barry M, Bradshaw C. Midwives' experiences of caring for women with early pregnancy loss in an Irish maternity hospital. British Journal of Midwifery. Vol. 26, No.12, 2018, https://doi.org/10.12968/bjom.2018.26.12.796.
- <sup>107</sup> Gov.UK. Register a stillbirth. <a href="https://www.gov.uk/register-stillbirth">https://www.gov.uk/register-stillbirth</a>.
- <sup>108</sup>Births and Deaths Registration Act 1953, <a href="http://www.legislation.gov.uk/ukpga/Eliz2/1-2/20">http://www.legislation.gov.uk/ukpga/Eliz2/1-2/20</a>
- <sup>109</sup> Bigrigg MA, Read MD. Management of women referred to early pregnancy assessment unit: care and cost effectiveness. Br Med J. 1991;302(6776):577–9.

<sup>&</sup>lt;sup>110</sup> NICE. Ectopic pregnancy and miscarriage: diagnosis and initial management [NG126]. Published: 17 April 2019; Last updated: 24 November 2021. Available at <a href="https://www.nice.org.uk/guidance/ng126">https://www.nice.org.uk/guidance/ng126</a>.

<sup>&</sup>lt;sup>111</sup> Quenby S, Ioannis D Gallos I D, Dhillon-Smith RK. Miscarriage matters: the epidemiological, physical, psychological, and economic costs of early pregnancy loss. Lancet 2021; 397: 1658–67.

<sup>112</sup> NHSH England. E-Learning for Health. Perinatal Post-mortem Consent programme. <a href="https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://www.e-https://

Ifh.org.uk/programmes/perinatal-post-mortem-consent/.

