HOUSE OF LORDS

Preterm Birth Committee

Report of Session 2024–25

Preterm birth: reducing risks and improving lives

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Preterm Birth Committee

The Preterm Birth Committee was appointed by the House of Lords on 24 January 2024, and re-appointed on 29 July 2024, to consider the prevention, and consequences, of preterm birth.

Membership

The Members of the Preterm Birth Committee were:

Baroness Blackstone
Viscount Colville of Culross
Baroness Cumberlege
Lord Hampton
Baroness Hughes of Stretford
Baroness Owen of Alderley Edge
Lord Patel (Chair)
Baroness Seccombe
Baroness Thornhill (until 20 May 2024)
Baroness Watkins of Tavistock
Lord Winston
Baroness Wyld

Declaration of interests

See Appendix 1.

A full list of Members' interests can be found in the Register of Lords' Interests:
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Publications

All publications of the Committee are available at:
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Committee staff

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Evidence is published online at https://committees.parliament.uk/committee/701/preterm-birth-committee/publications/ and available for inspection at the Parliamentary Archives (020 7219 3074).

Q in footnotes refers to a question in oral evidence.

SUMMARY

"Life before the neonatal unit is mostly irrelevant when you find yourself stood, post-partum, next to your baby in an incubator, hoping and wishing that you make it out safely … The vulnerability is beyond crippling."

"At exactly 30 weeks my twins were delivered by emergency caesarean. One night I was at Pilates and the next I was in hospital and supposedly a mother of two."

"The impact of prematurity does not end upon discharge from a neonatal unit."

"This experience has stayed with us for life."

As these quotes from parents demonstrate, preterm birth—when a baby is born before 37 weeks of pregnancy—can be sudden and unexpected. It can also have a significant, and sometimes lifelong, impact on babies and their families.

Evidence to our inquiry described this impact in stark detail. Preterm birth is the single biggest cause of neonatal mortality in the UK, and a leading contributor to deaths in childhood. Children who have been born prematurely are at increased risk of having long-term health conditions and disabilities. They are also more likely to have communication difficulties, autism and special educational needs.

Many parents will spend weeks or months caring for their preterm baby on a neonatal unit, often in a hospital a long way from home. The psychological impact of this experience can be profound and may not be fully evident until long after discharge home. It also creates practical and financial challenges; we heard that one in four families have to borrow money or increase their debt at this time in order to get by.

Thankfully, the majority of babies born prematurely go on to do well. Still, the case to reduce the incidence of preterm birth is clear. As well as improving outcomes for babies and their families, economic modelling suggests this would lead to significant cost savings across healthcare and education.

It is appropriate, therefore, that a target to reduce the preterm birth rate forms a key strand of the Government's national maternity safety ambition. However, data from the Office for National Statistics indicates that 7.9% of all births in England in 2022 were preterm births. The evidence we received was unequivocal: the target to reduce the rate to 6% by 2025 will not be met.

Many witnesses also expressed concern about the disparities in preterm birth rates and outcomes that exist between different socioeconomic and ethnic groups. The causes of these inequalities are complex and interconnected. As the 2025 deadline nears, we call on the Government to set out how it will revise the maternity safety ambition targets, to focus efforts on decreasing the rate of preterm birth across all groups of women.

We acknowledge that the prediction and prevention of preterm birth is made more challenging due to the wide range of factors that contribute to a woman's individual risk. Many women who give birth preterm have no apparent risk factors. Providing women with the information and support they need to optimise their general health prior to pregnancy, for example by stopping smoking, is therefore an important element of preterm birth prevention and should form part of the Government's women's health strategy.

Academics and clinicians emphasised that further research is also required, to enable us to identify the women at greatest risk and more effectively target preventive treatments. Improving our understanding of the biological processes that initiate preterm labour is particularly important. We heard, however, that we must increase research activity across all aspects of care relating to preterm birth.

It is important to recognise that we will never completely prevent preterm birth. Indeed, it may be a positive outcome in some instances, if continuing a pregnancy would present a risk to a mother or her baby. A key focus for our inquiry was, therefore, on how the impact of preterm birth could be reduced in cases when it cannot be avoided.

Appropriate clinical guidance is already in place. The Saving Babies' Lives Care Bundle, produced by NHS England and last updated in 2023, sets out a range of interventions aimed at improving outcomes for babies who are born preterm.

Witnesses told us that these interventions have clear, measurable benefits. They are, however, being implemented inconsistently; babies may receive different treatment depending on where in the country they are born. Progress has been made, particularly through the use of targeted implementation programmes, but should be expanded. Many maternity and neonatal services continue to face serious staffing pressures. Addressing these will be key to ensuring that the highest-quality care is available to all mothers and babies.

Enabling families to be involved fully in their baby's care while on the neonatal unit is another vital part of improving outcomes. Efforts to provide family integrated care are increasing, but practical barriers to making it a reality for all remain. Overnight accommodation for parents is rarely available, meaning they must repeatedly endure the distress of being separated from their baby. In a 2022 survey, 75% of parents said they did not have access to accommodation on the neonatal unit when their baby was critically ill. NHS England must reprioritise investment in parental accommodation to support the provision of family integrated care.

Parents continue to face challenges after discharge from hospital. Community healthcare professionals are often poorly equipped to provide the informed care and support they need, during what can be a difficult period of transition. While national guidelines set out that preterm babies should have a series of follow-up assessments as they prepare to start school, delivery of these is, at best, inconsistent. In many cases, the assessments do not happen at all. Urgent action must be taken to address this issue.

We thank all the witnesses who gave evidence to this inquiry, but particularly those who shared their personal experiences. Their accounts made clear why more must be done to support preterm babies and their families to thrive. We hope that the key findings of our report, set out on the following pages, will form part of the co-ordinated effort that is needed to ensure that this happens.

SUMMARY OF CONCLUSIONS AND RECOMMENDATIONS

1. We heard stark evidence about the impact of preterm birth. It is a major contributor to neonatal mortality and morbidity, and can lead to significant, and often lifelong, adverse consequences for individuals born preterm. Neonatal care following a preterm birth is often a traumatic experience, and its impact on parents and families can endure long after discharge from hospital. (Paragraph 66)

2. A co-ordinated effort to reduce the incidence of preterm birth and mitigate its negative consequences is therefore vital. As well as improving outcomes for babies and their families, there is a clear economic case for this; reducing the immediate and longer-term impacts of preterm birth could generate substantial cost savings within healthcare and education. (Paragraph 67)

3. We welcome that the current maternity safety ambition recognises the importance of lowering the rate of preterm birth. It is clear, however, that the target to reduce the rate to 6% by 2025 will not be met. We are persuaded that a more nuanced target, or set of targets, would be more effective in enabling improvements to be monitored. A metric focused on addressing the disparities in preterm birth rates and outcomes across different socioeconomic and ethnic groups deserves particular consideration. (Paragraph 68)

4. *In its response to this report, the Government should set out its plans to revise the current national maternity safety ambition, focusing particularly on targets that will support efforts to reduce the incidence and impact of preterm birth.* (Paragraph 69)

5. A woman's individual risk of giving birth preterm is determined by a complex set of interrelated factors. Predicting and preventing preterm birth is therefore challenging. While the Committee heard that screening and the targeting of treatment could be improved, further research is required to understand the biological mechanisms underlying preterm labour, identify those women at greatest risk, and determine which interventions would most effectively support prevention. (Paragraph 100)

6. Optimising women's health prior to pregnancy is an important element of preterm birth prevention. This includes addressing social deprivation and potential risk factors such as smoking, drug use, obesity and mental health problems. An increased focus on this is likely to be necessary to achieve the kind of reduction in the preterm birth rate envisaged by the maternity safety ambition. We welcome, therefore, the emphasis the new Government has placed on prevention and prioritising women's general health. (Paragraph 108)

7. *The Government should set out how, as part of its strategy for women's health, it will ensure that all women have access to information and advice on pregnancy planning and preconception health at an appropriate time.* (Paragraph 109)

8. While there is evidence to suggest that implementing existing guidance consistently would improve outcomes for preterm babies, and potentially reduce the preterm birth rate, there is currently significant variation in care between hospitals and regions. Regional networks and bodies have an important role to play in improving the implementation of guidance. Toolkits such as PERIPrem provide useful models for successful implementation that could be adopted more widely. (Paragraph 132)

9. *The Government and NHS England must take further action to ensure the consistent implementation of clinical guidance relating to preterm birth, particularly the perinatal optimisation interventions set out in the Saving Babies' Lives Care Bundle. Every region should have the resources to adopt the methodology of implementation programmes that have been shown to be effective, and continue to strengthen maternal medicine and neonatal networks.* (Paragraph 133)

10. Despite recent improvements to staffing levels in some areas, maternity and neonatal services continue to be affected by significant staff shortages. This constrains the delivery of optimal, safe care for preterm babies and their families. (Paragraph 149)

11. *It is imperative that the Government and NHS England meet the commitments to develop the maternity and neonatal workforce set out in the NHS Long-term Workforce Plan.* (Paragraph 150)

12. Supporting parents to be involved closely in their babies' care while on the neonatal unit is an essential part of improving outcomes for preterm babies and their families. However, barriers to the delivery of family integrated care continue to exist. The availability of parental accommodation is inadequate in most cases, despite the promise of investment set out in the NHS Long Term Plan. (Paragraph 165)

13. *NHS England should publish the findings of its maternity and neonatal estates survey, setting out what proportion of neonatal units are currently able to provide sufficient accommodation for all families, as per the updated service specification for neonatal critical care.* (Paragraph 166)

14. *In addition, the Government and NHS England should set out their plans for future investment in parental accommodation on neonatal units, to support improved provision of family integrated care.* (Paragraph 167)

15. The period following discharge home from the neonatal unit can be a challenging time for preterm babies and their families. Many parents will require emotional, as well as practical, support as they begin to process the psychological impact of their time in neonatal care. Parents report that community healthcare professionals are often unable to provide the informed care and advice they need. (Paragraph 187)

16. Specialist mental health and neonatal outreach services can play a key role in delivering such support. However, we heard that these are not always available. While health visitors do reach all families, they are poorly equipped to meet the specific needs of preterm babies and their parents due to their limited training on the impacts of prematurity. (Paragraph 188)

17. *The Government and NHS England should detail the steps they are taking to ensure equitable access to neonatal outreach and perinatal mental health services for all families that experience preterm birth.* (Paragraph 189)

18. *NHS England should work with training providers to embed opportunities to develop specialist knowledge of the needs of preterm babies and their families into health visitor training and continuous professional development, with protected training time.* (Paragraph 190)

19. The Committee heard that follow-up assessments for children who were born preterm are essential in identifying additional support needs and opportunities for beneficial early intervention before children start school.

Yet there is worrying evidence that these are not consistently delivered at ages two and four, despite being recommended in NICE guidance. (Paragraph 201)

20. Provision of the assessment at age four appears to be especially low. We saw no evidence that action is being taken to address this failure, or to hold the relevant services accountable for delivery. Indeed, there even appears to be some uncertainty about where responsibility for these assessments lies. (Paragraph 202)

21. *The Government and NHS England must take swift action to determine why the follow-up assessments recommended by NICE are not being consistently delivered, in particular at age four, and prioritise work to address this.* (Paragraph 203)

22. We support the ambition of programmes such as the Prem Aware Award scheme to increase awareness of the impacts of prematurity in schools. Enhancing understanding among education professionals has the potential to facilitate the transition to school for families, enable appropriate support to be provided during school and improve outcomes for children born prematurely. (Paragraph 217)

23. Research is an essential component of optimising care and outcomes for mothers at risk of preterm birth and babies who are born prematurely. A greater focus on pregnancy and neonatal research is needed, alongside increased funding, to make progress in understanding the fundamental mechanisms of preterm labour, developing more effective interventions, and ensuring clinical guidance is implemented effectively. (Paragraph 240)

Preterm birth: reducing risks and improving lives

CHAPTER 1: INTRODUCTION

Background to the inquiry

Preterm birth

1. Preterm birth refers to when a baby is born before 37 weeks of pregnancy. The World Health Organization classifies preterm births according to gestational age[1] as follows:

    - Extremely preterm (less than 28 weeks)
    - Very preterm (28 to less than 32 weeks)
    - Moderate to late preterm (32 to 36 weeks).

    From 37 weeks a pregnancy is considered full term.[2]

2. Preterm labour may start by itself (spontaneous preterm labour). It may also be initiated by a clinician, if this is believed to be the safest option for the mother or baby (provider initiated, or iatrogenic, preterm labour).[3]

3. The latest available figures for England[4] show that there were 44,219 preterm live births[5] and 1,687 preterm stillbirths[6] in 2022. This represents 7.9% of all births that year.[7] In Wales, the proportion of live births prior to 37 weeks' gestation was 8.1% in 2022.[8] The latest figure from Scotland was slightly

1 See glossary.
2 World Health Organization, 'Preterm Birth': https://www.who.int/news-room/fact-sheets/detail/preterm-birth [accessed 20 June 2024]
3 NHS, 'Premature Labour and Birth': https://www.nhs.uk/pregnancy/labour-and-birth/signs-of-labour/premature-labour-and-birth/ [accessed 20 June 2024]
4 Healthcare is a devolved matter. Data available at Office for National Statistics (ONS), 'Birth Characteristics in England and Wales: 2022': https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthcharacteristicsinenglandandwales/2022#births-data [accessed 8 July 2024]
5 Preterm live birth is defined here as when a baby is born between 24 weeks and zero days' (24+0) and 36 weeks and six days' (36+6) gestation and shows signs of life. This is different from the definition used by the ONS, but consistent with the definition used by the Government in relation to its ambition to reduce the rate of preterm birth. See also footnote 7, para 4 and glossary.
6 A birth between 24+0 and 36+6 weeks' gestation where the baby shows no signs of life. See glossary.
7 In 2021, the Department of Health and Social Care clarified that the data it used to monitor preterm birth rates included figures for live births and stillbirths for babies of a gestational age between 24+0 and 36+6 weeks. We have followed this approach when calculating annual preterm birth rates. We note, however, that preterm birth rate figures cited in other sources may also record births occurring before 24 weeks' gestation, and may exclude stillbirths. Written evidence to the Commons Health and Social Care Committee, from the Department of Health and Social Care (EPE0026). Data available at ONS, *Dataset—Birth Characteristics* (May 2024): https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/birthcharacteristicsinenglandandwales [accessed 20 June 2024]
8 ONS, 'Birth Characteristics in England and Wales: 2022': https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthcharacteristicsinenglandandwales/2022#births-data [accessed 8 July 2024]

higher, at 8.4%.[9] Analysis by the Euro-Peristat network found that the median preterm birth rate in Europe in 2019 was 6.9%. Rates per country varied from 5.3% to 11.3%.[10] According to WHO estimates, in 2020, 9.9% of babies born alive worldwide were preterm.[11]

Table 1: Preterm live births and stillbirths in England in 2022

Gestational age	Live births	Stillbirths
24 to 27 weeks/Extremely preterm	1,917	716
28 to 31 weeks/Very preterm	4,374	411
32 to 36 weeks/Moderate to late preterm	37,928	560
Total	44,219	1,687

Source: ONS, 'Birth characteristics in England and Wales: 2022': https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthcharacteristicsinenglandandwales/2022#births-data [accessed 20 June 2024]

4. Central to recent Government policy on preterm birth has been the national maternity safety ambition, first launched in 2015. The initial aim was to reduce the number of stillbirths, neonatal and maternal deaths, and serious neonatal brain injuries by half between 2010 and 2030.[12] A revised ambition, published in 2017, brought the deadline forward to 2025. It also introduced an additional target to reduce the rate of preterm birth from 8% of births to 6%.[13] The new goal recognised the interrelationship between preterm birth and the adverse pregnancy outcomes targeted in the original ambition.[14] Indeed, the then Government stated that the ambition would not be achieved "without … focusing on reducing the number of babies born preterm each year".[15]

Provision and co-ordination of care

5. The provision of care in relation to preterm birth involves both maternity and neonatal services, since babies who are born preterm frequently require specialist critical care after birth.[16] In England, maternity services are purchased through the local integrated care board (ICB).[17] Each ICB is a partner in an integrated care system (ICS).[18] A local maternity and neonatal

9 Data available at Public Health Scotland, 'Births in Scotland: Year ending 31 March 2023': https://www.publichealthscotland.scot/publications/births-in-scotland/births-in-scotland-year-ending-31-march-2023/ [accessed 12 July 2024]

10 Euro PERISTAT, *European Perinatal Health Report* (2022) pp 8–10: https://www.europeristat.com/images/Euro-Peristat_Fact_sheets_2022_for_upload.pdf [accessed 11 July 2024]

11 These figures are for live births before 37 weeks' gestation. World Health Organization, 'Born too soon: decade of action on preterm birth', p 14: https://www.who.int/publications/i/item/9789240073890 [accessed 11 July 2024]

12 Department of Health and Social Care, 'New ambition to halve rate of stillbirths and infant deaths' (November 2015): https://www.gov.uk/government/news/new-ambition-to-halve-rate-of-stillbirths-and-infant-deaths [accessed 20 June 2024]

13 Department of Health, *Safer Maternity Care* (November 2017) pp 4–5: https://assets.publishing.service.gov.uk/media/5a74eacbe5274a3cb286839b/Safer_maternity_care_-_progress_and_next_steps.pdf [accessed 20 June 2024]

14 See para 27.

15 Department of Health, *Safer Maternity Care*, pp 4–5

16 NHS, *Premature labour and birth*

17 See Table 2 and glossary.

18 See Table 2 and glossary.

system (LMNS) acts as "the maternity and neonatal arm of the ICS".[19] Neonatal critical care was previously a specialist service purchased directly by NHS England, but these responsibilities have begun to be transferred to ICBs in recent months.[20] Both maternity and neonatal services are delivered by NHS trusts.

Table 2: Organisations involved in the funding and delivery of maternity and neonatal care

Organisation	Function
Integrated care systems (ICSs)	Bring together organisations including local government, integrated care boards and the voluntary sector to develop health and care strategies for the geographical area they cover.
Integrated care boards (ICBs)	Have responsibility for planning and funding most NHS services in the geographical area they cover.
Local maternity and neonatal systems (LMNSs)	Align with ICSs. Bring together purchasing bodies, hospital trusts and service users to provide and improve maternity and neonatal care.
Maternal medicine networks (MMNs)	Groups of NHS providers, based in the same geographical area, that work together to provide specialist antenatal and postnatal care for women with complex medical conditions.
Neonatal operational delivery networks (ODNs)	Groups of NHS providers, based in the same geographical area, that work together to ensure that care is delivered in a co-ordinated way across different types of neonatal unit.
NHS trusts	Provide services including acute and community care in the geographical area they cover.
Third-sector organisations	National charities such as Tommy's and Bliss, and smaller regional organisations, provide funding for maternity and neonatal research, as well as guidance and support for babies and families.

Source: House of Commons Library, The structure of the NHS in England, Research Briefing, CBP 7206, July 2023; National Audit Office, Introducing Integrated Care Systems: joining up local services to improve health outcomes (October 2022): https://www.nao.org.uk/wp-content/uploads/2022/10/Integrated-Care-Systems-Funding-and-accountability-for-local-health-and-care-Summary.pdf [accessed 22 October 2024] and NHS England, 'Three year delivery plan for maternity and neonatal services': https://www.england.nhs.uk/long-read/three-year-delivery-plan-for-maternity-and-neonatal-services/ [accessed 22 October 2024]

6. Care is also co-ordinated regionally in England by 14 maternal medicine networks (MMNs) and 10 neonatal operational delivery networks (ODNs).[21] These are based on geographical areas where hospitals work together and

19 NHS England, 'Three year delivery plan for maternity and neonatal services': https://www.england.nhs.uk/long-read/three-year-delivery-plan-for-maternity-and-neonatal-services/ [accessed 20 June 2024]

20 NHS England, 'NHS England commissioning functions for delegation to integrated care systems': https://www.england.nhs.uk/publication/nhs-england-commissioning-functions-for-delegation-to-integrated-care-systems/ [accessed 12 July 2024]

21 Written evidence from Department of Health and Social Care (PRT0081); NHS England, *Implementing the Recommendations of the Neonatal Critical Care Transformation Review* (January 2020): https://www.england.nhs.uk/wp-content/uploads/2019/12/Implementing-the-Recommendations-of-the-Neonatal-Critical-Care-Transformation-Review-FINAL.pdf [accessed 20 June 2024]

can span several LMNSs. Equally, some LMNSs sit across more than one ODN, as ICB, ODN and trust boundaries do not always align.[22] MMNs co-ordinate specialist care for women with complex medical conditions that predate or arise during pregnancy.[23] ODNs aim to "ensure that the different levels of [neonatal] care are accessible for all babies" and that "the right level of care is provided as near to home as possible."[24]

7. Neonatal care is categorised according to intensity and delivered across three types of unit: neonatal intensive care units (NICUs), local neonatal units (LNUs) and special care units (SCUs).[25] As not all units can provide all levels of care, preterm infants may be treated at more than one hospital.[26] ODNs operate specialised transport services to support transfers between sites.[27]

National targets, guidance and policy

8. In 2015, NHS England commissioned a national maternity review. Its report, *Better Births*, was published the following year.[28] The Maternity Transformation Programme was then established to implement the review's "vision for safer and more personalised care across England" and deliver the national ambition.[29] A core aspect of this vision was the continuity of carer staffing model.[30] *Better Births* cited evidence that this led to improved safety and clinical outcomes, better co-ordination of care and a reduction in the incidence of preterm birth.[31] *Better Births* also recommended that a dedicated review of neonatal services should be undertaken. The conclusions of this evaluation, the Neonatal Critical Care Transformation Review, were published in 2019.[32]

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22 For example, the Bedfordshire, Luton and Milton Keynes ICB oversees neonatal units in both the East of England ODN and the Thames Valley and Wessex ODN. Bedfordshire, Luton and Milton Keynes ICS, 'Our Area': https://blmkhealthandcarepartnership.org/about/our-area/ [accessed 2 September 2024]; East of England Neonatal ODN, 'About Us': https://eoeneonatalpccsicnetwork.nhs.uk/neonatal/about-us/ [accessed 2 September 2024]; NHS England South East, 'Our region': https://neonatalnetworkssoutheast.nhs.uk/about/our-region/ [accessed 2 September 2024]

23 Written evidence from Department of Health and Social Care (PRT0081)

24 British Association of Perinatal Medicine, 'Neonatal networks': https://www.bapm.org/pages/19-neonatal-networks [accessed 2 September 2024]; NHS England, *Neonatal Critical Care Clinical Network Specification (May 2023)*: https://www.england.nhs.uk/wp-content/uploads/2024/05/PRN231107-neonatal-critical-care-network-specification-2023-.pdf [accessed 2 September 2024]

25 From the highest to the lowest level of support and monitoring, the types of care are intensive care, high dependency care, special care and transitional care. Transitional care is delivered by parents, with support from clinical staff. Bliss, 'How does neonatal care work?': https://www.bliss.org.uk/parents/in-hospital/about-neonatal-care/how-does-neonatal-care-work [accessed 20 June 2024]; NHS England, Implementing the Recommendations of the Neonatal Critical Care Transformation Review, pp 6–7

26 NICUs provide all levels of care; LNUs provide short-term intensive care, as well as high dependency and special care for babies and families in their local population; and SCUs provide special and transitional care for their local population. Bliss, 'How does neonatal care work?': https://www.bliss.org.uk/parents/in-hospital/about-neonatal-care/how-does-neonatal-care-work [accessed 20 June 2024]

27 British Association of Perinatal Medicine, 'Neonatal networks': https://www.bapm.org/pages/19-neonatal-networks [accessed 2 September 2024] and NHS England, *Schedule 2—The Services* (2015): https://www.england.nhs.uk/commissioning/wp-content/uploads/sites/12/2015/01/e08-serv-spec-neonatal-critical-transp.pdf [accessed 20 June 2024]

28 National Maternity Review, *Better Births* (2016): https://www.england.nhs.uk/wp-content/uploads/2016/02/national-maternity-review-report.pdf [accessed 11 July 2024]

29 NHS England, 'Maternity Transformation Programme': https://www.england.nhs.uk/mat-transformation/ [accessed 10 July 2024]

30 See Box 5.

31 National Maternity Review, *Better Births*, p 46

32 NHS England, Implementing the Recommendations of the Neonatal Critical Care Transformation Review

9. The delivery of the maternity safety ambition has been supported since 2016 by the Saving Babies' Lives Care Bundle (SBLCB), a set of best-practice guidelines for maternity and neonatal services published by NHS England. It now includes a strand focused specifically on preterm birth.

Box 1: The Saving Babies' Lives Care Bundle

The first iteration of the Saving Babies' Lives Care Bundle was made available to maternity units in England in 2016. It set out national guidance for providers and commissioners on reducing early neonatal deaths or stillbirths, grouped into four 'elements'.[33]

In 2019 a revised version of the bundle was launched. This introduced an additional element aimed at "reducing the number of preterm births and optimising care when preterm delivery cannot be prevented." It recommended interventions including assessing all women for risk of preterm birth at their initial pregnancy booking; and ensuring that women at imminent risk of preterm labour were offered transfer to a hospital with appropriate neonatal cot facilities.[34]

A third iteration of the bundle was published in June 2023. It includes expanded guidance relating to preterm birth. In particular, it identifies nine specific 'perinatal optimisation' interventions, aimed at improving outcomes for the baby when preterm labour is suspected or established. It also sets out that each provider should have a multidisciplinary 'preterm birth lead team', incorporating obstetric, midwifery and neonatal staff.[35] Providers of maternity services had a responsibility to implement this iteration by March 2024.[36]

10. The National Institute for Health and Care Excellence (NICE) also provides recommendations via guideline NG25 on preterm labour and birth in women with singleton pregnancies;[37] NG137 on care for women with a twin or triplet pregnancy, who have a higher risk of spontaneous preterm labour;[38] NG124 on specialist neonatal respiratory care for babies born preterm;[39] and NG72 on developmental follow-up assessments for children who were born preterm.[40] Additional guidelines and toolkits relating to preterm birth are published by bodies including the Royal College of Obstetricians and

33 NHS England, *Saving Babies' Lives* (March 2016): https://www.england.nhs.uk/wp-content/uploads/2016/03/saving-babies-lives-car-bundl.pdf [accessed 20 June 2024)

34 NHS England, *Saving Babies' Lives Version Two* (March 2019): https://www.england.nhs.uk/wp-content/uploads/2019/07/saving-babies-lives-care-bundle-version-two-v5.pdf [accessed 20 June 2024]

35 Commentary on individual recommended interventions from the latest SBLCB is included in Chapters 3 and 4 of this report. NHS England, *Saving Babies' Lives Version Three* (July 2023): https://www.england.nhs.uk/wp-content/uploads/2023/05/PRN00614-Saving-babies-lives-version-three-a-care-bundle-for-reducing-perinatal-mortality.pdf [accessed 20 June 2024]

36 NHS England, 'Three year delivery plan for maternity and neonatal services': https://www.england.nhs.uk/long-read/three-year-delivery-plan-for-maternity-and-neonatal-services/ [accessed 20 June 2024]

37 Published in 2015 and updated in 2022. NICE, 'Preterm labour and birth': https://www.nice.org.uk/guidance/ng25 [accessed 20 June 2024]

38 Published in 2019 and updated in 2024. NICE, 'Twin and triplet pregnancy': https://www.nice.org.uk/guidance/ng137 [accessed 20 June 2024]

39 Published in 2019. NICE, 'Specialist neonatal respiratory care for babies born preterm': https://www.nice.org.uk/guidance/NG124 [accessed 18 July 2024]

40 Published in 2017. NICE, 'Developmental follow-up of children and young people born preterm': https://www.nice.org.uk/guidance/ng72 [accessed 20 June 2024]

Gynaecologists (RCOG) and the British Association of Perinatal Medicine (BAPM).[41]

11. The NHS Long Term Plan, published in January 2019, set out that "the prevalence of preterm birth is increasing", and "more focus on preterm mortality is needed to achieve substantial reductions in overall perinatal mortality rates" in line with the national ambition. It highlighted the upcoming publication of the second version of the SBLCB and stated that the NHS would "encourage development of specialist preterm birth clinics".[42] The plan also set an aim for "most women" to be offered midwife continuity of carer by 2021, with efforts targeted particularly towards women from Black and minority ethnic backgrounds, and more deprived areas.[43]

12. The plan identified that neonatal critical care capacity must "keep pace" with the growing incidence of preterm birth and improvements in survival rates for newborns. Commitments for neonatal services included introducing additional intensive care cots; developing the neonatal nursing workforce; and supporting families to be more involved in their baby's care, by improving accommodation for parents and introducing care co-ordinators.[44]

13. These objectives were also highlighted in 2019 Neonatal Critical Care Transformation Review. It identified too the need to develop transport pathways and ensure that extremely preterm babies are born "in the right setting with an on-site NICU".[45]

14. Investment and initiatives related to the 2019 commitments have since been announced, including via the NHS Long Term Workforce Plan and the 2023 three-year delivery plan for maternity and neonatal services.[46] These also respond to recommendations made following investigations into particular maternity services providers across the country, such as the 2022 Ockenden review. This also identified nationally applicable "essential actions", including several relating to the care of women at high risk of preterm birth and preterm babies.[47]

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41 See, for example, Royal College of Obstetricians and Gynaecologists, 'Care of Women Presenting with Suspected Preterm Prelabour Rupture of Membranes from 24+0 Weeks of Gestation': https://www.rcog.org.uk/guidance/browse-all-guidance/green-top-guidelines/care-of-women-presenting-with-suspected-preterm-prelabour-rupture-of-membranes-from-24plus0-weeks-of-gestation-green-top-guideline-no-73/ [accessed 17 September 2024]; British Association of Perinatal Medicine, 'Perinatal Optimisation Pathway': https://www.bapm.org/pages/perinatal-optimisation-pathway [accessed 18 July 2024]

42 NHS, 'Maternity and neonatal services': https://www.longtermplan.nhs.uk/online-version/chapter-3-further-progress-on-care-quality-and-outcomes/a-strong-start-in-life-for-children-and-young-people/maternity-and-neonatal-services/ [date accessed 20 June 2024]

43 NHS, *Maternity and neonatal services*

44 *Ibid.*

45 NHS England, Implementing the Recommendations of the Neonatal Critical Care Transformation Review, p 11

46 NHS England, 'NHS announces £127 million maternity boost for patients and families': https://www.england.nhs.uk/2022/03/nhs-announces-127m-maternity-boost-for-patients-and-families/ [accessed 11 July 2024]; NHS England, 'NHS Long Term Workforce Plan' https://www.england.nhs.uk/long-read/nhs-long-term-workforce-plan-2/ [accessed 20 June 2024]

47 Ockenden Maternity Review, *Findings, Conclusions and Essential Actions from the Independent Review of Maternity Services at the Shrewsbury and Telford Hospital NHS Trust* (HC 1219): https://www.ockendenmaternityreview.org.uk/wp-content/uploads/2022/03/FINAL_INDEPENDENT_MATERNITY_REVIEW_OF_MATERNITY_SERVICES_REPORT.pdf [accessed 7 November 2024]; See also the 2022 review into maternity and neonatal services in East Kent: Department of Health and Social Care, 'Maternity and neonatal services in East Kent: Reading the signals' (October 2022): https://www.gov.uk/government/publications/maternity-and-neonatal-services-in-east-kent-reading-the-signals-report [accessed 8 July 2024]

15. Standards in NHS maternity services have remained under close scrutiny in recent months, for example through the work of the All-Party Parliamentary Group on Birth Trauma[48] and the ongoing review of services at Nottingham University Hospitals NHS Trust.[49] The recent investigation into the NHS in England conducted by the Rt Hon Professor the Lord Darzi of Denham raised a number of issues, including "huge inequalities" in maternity care among different groups of the population.[50]

16. The Labour Party stated in its 2024 manifesto that:

> "Childbirth should not be something women fear or look back on with trauma. Labour will ensure that trusts failing on maternity care are robustly supported into rapid improvement."

It also committed to "train thousands more midwives" and to "prioritise women's health" as part of NHS reforms.[51]

The inquiry and the work of the Committee

17. The House of Lords Preterm Birth Committee was established in January 2024 to "consider the prevention, and consequences, of preterm birth."[52] These terms of reference reflect the two principal questions that guided our work: first, how the overall incidence of preterm birth in England could be reduced; and secondly, how outcomes for babies, parents and families could be improved when preterm birth cannot be avoided.

18. Our focus throughout has been on this single possible outcome of pregnancy. We recognise, however, the relevance of the wider pressures faced by maternity and neonatal services for providing the best possible care to mothers and preterm babies. Consequently, our report also addresses these issues. As healthcare services are a devolved matter, the evidence we received, and the conclusions and recommendations we have subsequently drawn, concentrate on the situation in England.

19. During our inquiry, we were reminded that most babies who are born preterm will have positive outcomes, and we have been alert to this throughout. Witnesses also emphasised, however, that in some cases the impacts of preterm birth can be significant and severe. The consequences of preterm birth are considered in Chapter 2 of this report. This chapter also examines progress towards the ambition to reduce the rate of preterm birth by 2025.

20. Prevention is discussed in Chapter 3. Witnesses set out the wide range of factors that influence the likelihood of giving birth preterm, as well as the challenges of identifying women who are at risk. We reviewed the effectiveness of current screening arrangements and preventive obstetric treatments. We

48 All-Party Parliamentary Group on Birth Trauma, *Listen to Mums: Ending the Postcode Lottery on Perinatal Care*: https://www.theo-clarke.org.uk/sites/www.theo-clarke.org.uk/files/2024-05/Birth%20Trauma%20Inquiry%20Report%20for%20Publication_May13_2024.pdf [accessed 5 July 2024]

49 Ockenden Maternity Review, 'Terms of reference: Independent maternity review—Nottingham University Hospitals NHS Trust' (September 2023): https://www.ockendenmaternityreview.org.uk/terms-of-reference/ [accessed 17 September 2024]

50 Prof Lord Darzi of Denham OM KBE FRS, *Independent Investigation of the National Health Service in England* (September 2024), pp 38–40: https://assets.publishing.service.gov.uk/media/66e1b49e3b0c9e88544a0049/Lord-Darzi-Independent-Investigation-of-the-National-Health-Service-in-England.pdf [accessed 16 September 2024]s

51 Labour Party, *Labour Party Manifesto 2024* (June 2024), p 98, 203: https://labour.org.uk/wp-content/uploads/2024/06/Labour-Party-manifesto-2024.pdf [accessed 15 July 2024]

52 Liaison Committee, *New committee activity in 2024* (1st Report, Session 2023–4, HL Paper 12)

also explored how primary prevention—improving women's health prior to pregnancy—might help to reduce preterm birth rates.

21. Chapters 4 and 5 address how outcomes following preterm birth could be optimised. We examined the obstacles to implementing best practice guidance for obstetric and neonatal care, and how these could be overcome. We also took evidence on the role of family-integrated care on neonatal units and follow-up care after discharge from hospital.

22. Evidence to the inquiry identified many areas where additional preterm birth-related research is needed. Witnesses also highlighted barriers to conducting such research. These issues are covered in Chapter 6.

23. In producing this report, we have sought to keep the needs and experiences of babies, children, parents and families at the forefront of our considerations. We are very grateful to all those who gave evidence to our inquiry, but we extend particular thanks to those who felt able to share insights based on their personal experiences. It was vital to hear the views of parents as part of our inquiry, as well as the perspective of adults who were born prematurely. Some who provided written evidence to the Committee wished to remain anonymous; we understood and accepted these requests, given the nature of the subject matter.

24. We are also grateful to our specialist adviser, Dr Eleri Adams, Consultant Neonatologist at Oxford University Hospitals NHS Foundation Trust, President of BAPM and National Neonatology Specialty Lead for the Getting It Right First Time (GIRFT) programme.[53] Her expertise has assisted us greatly in our deliberations throughout the inquiry. In addition, the Committee wishes to thank the members of staff who supported us in our work: Eleanor Clements (Clerk), Babak Winstanley-Sharples (Policy Analyst), Mark Gladwell (Committee Operations Officer) and Alec Brand (Media and Communications Officer).

25. The Committee met for the first time on 31 January 2024. A call for written evidence was issued in March, and is reprinted in Appendix 3. Over the course of our inquiry, we received 86 written evidence submissions and heard from 54 witnesses in 20 oral evidence sessions. A list of those who gave us written and oral evidence is included in Appendix 2 and is available on our website.[54]

26. With the dissolution of Parliament prior to the general election in July, the Committee's inquiry was suspended. The Committee resumed its work following its reappointment on 29 July. This report inevitably focuses on policies and performance under the previous Conservative Government, but our conclusions and recommendations are addressed to the new Government. The evidence we heard convinces us that there is scope for improvements that will deliver lasting benefits for preterm babies and their families. We hope that this report will be of value to the Government as it shapes its policy in this important area, and that the many charities and organisations that gave evidence will work collectively to ensure that our recommendations to improve care and outcomes are taken forward.

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53 "A national NHS England programme designed to improve the treatment and care of patients through in-depth review of services, benchmarking, and presenting a data-driven evidence base to support change." NHS England, 'Getting It Right First Time (GIRFT)': https://gettingitrightfirsttime.co.uk/ [accessed 17 September 2024]

54 Preterm Birth Committee, 'Summary': https://committees.parliament.uk/committee/701/preterm-birth-committee/

CHAPTER 2: THE CASE FOR CHANGE

The impact of preterm birth

Impact on babies born preterm

27. Clinical guidance from NICE states that preterm birth is "the single biggest cause of neonatal mortality and morbidity in the UK".[55] Three-quarters of all stillbirths in England in 2022 were preterm births.[56] According to figures from the Sands and Tommy's Joint Policy Unit (JPU), 75% of neonatal deaths[57] in 2021 were among babies born before 37 weeks' gestational age.[58] The British Association of Perinatal Medicine (BAPM) stated that this figure reached 79% in 2023.[59]

28. Preterm birth is also a contributor to mortality in childhood.[60] We heard from the National Child Mortality Database (NCMD) that:

> "The impact of [an infant's] preterm birth is substantial across their childhood, with ex-preterm infants having increased risk of death at least until 10 years of age, and likely beyond."[61]

According to its analysis, "of all the childhood deaths below 10 years of age, 46% were caused by preterm birth".[62] It has therefore been attributed as "the leading cause of child death up to the age of 18".[63]

29. According to NICE, "babies who survive preterm birth have increased rates of disability."[64] One study estimated that 4.2% of all surviving preterm babies will have a severe disability at age 18, while 18.5% will have a milder disability.[65] We heard that preterm birth is "by far the biggest cause" of perinatal brain injury, with severe brain injury seen in 26 per 1,000 live preterm births, compared to 3.5 per 1,000 live term births.[66] Such injuries are associated with a substantially increased risk of cerebral palsy.[67] Babies born preterm are also "vulnerable for persistent feeding and/or swallowing difficulties."[68]

30. A 2020 cohort study demonstrated a strong association between decreasing gestational age at birth and an increased risk of hospital admissions during childhood in England: the admission rate of children born at less than 28

55 NICE, 'Preterm labour and birth': https://www.nice.org.uk/guidance/ng25 [accessed 20 June 2024]
56 Data available at ONS, 'Birth Characteristics in England and Wales: 2022': https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthcharacteristicsinenglandandwales/2022#births-data [accessed 8 July 2024]
57 See glossary.
58 Written evidence from Sands and Tommy's Joint Policy Unit (PRT0045)
59 Written evidence from British Association of Perinatal Medicine (PRT0042)
60 Q 9 (Prof Marian Knight MBE); Written evidence from Sands and Tommy's Joint Policy Unit (PRT0045)
61 Written evidence from National Child Mortality Database (PRT0060)
62 *Ibid.*
63 Q 9 (Prof Marian Knight MBE)
64 NICE, 'Preterm labour and birth': https://www.nice.org.uk/guidance/ng25 [accessed 20 June 2024]
65 Lindsay J. Mangham et al, 'The Cost of Preterm Birth Throughout Childhood in England and Wales', *American Academy of Pediatrics, Vol 123, Issue 2 (2009), e312-327:* https://publications.aap.org/pediatrics/article-abstract/123/2/e312/69430/The-Cost-of-Preterm-Birth-Throughout-Childhood-in [accessed 07 November 2024]
66 Written evidence from British Association of Perinatal Medicine (PRT0042)
67 Q 69 (Prof Chris Gale)
68 Written evidence from Royal College of Speech and Language Therapy Clinical Excellence Network (PRT0047)

weeks' gestational age was five times higher than that for children born at 40 weeks.[69] A more recent study based on healthcare data from Finland and Norway found that, in addition to elevated risks of many individual health conditions, preterm birth was associated with diverse multimorbidity patterns (the presence of two or more long-term health conditions) among children aged between 10 and 18.[70] Professor David Edwards, Professor of Paediatrics and Neonatal Medicine at King's College London, suggested that the increased incidence of conditions such as high blood pressure and chronic obstructive airways disease among adolescents who were born preterm "augurs very badly for the future".[71]

31. Professor Samantha Johnson, Professor of Child Development at the University of Leicester, and Professor Neil Marlow, Emeritus Professor of Neonatal Medicine at the Institute for Women's Health, University College London, emphasised that preterm birth can also affect children's neurodevelopment:

> "Although a small proportion of preterm babies go on to have physical disabilities, the most common adverse outcomes are cognitive impairments (such as difficulties with memory, attention, and problem solving), motor impairments (difficulties with fine and gross motor skills), social and emotional problems (particularly anxiety, depression and withdrawn behaviour), and social and communication difficulties."

They highlighted that children who were born preterm are also more likely to have attention-deficit/hyperactivity disorder (ADHD), autism spectrum disorder, special educational needs (SEN) and learning difficulties than children who were born at term.[72] Studies have demonstrated that the percentage of children defined as having SEN during primary school increased with decreasing gestational age, from 29.0% among those born at full term to 82.6% among children born at 24 weeks; and that lower educational attainment among children who were born preterm is observed up to age 16.[73]

32. Professor Dieter Wolke, Professor of Developmental Psychology and Individual Differences at the University of Warwick, told us that many of the effects of preterm birth, including lower cognitive performance, "continue into adulthood with little narrowing of the differences to those born full term". He suggested that preterm birth can also have a detrimental effect on an individual's ability to "master life tasks" as they transition into adulthood.[74]

33. Individuals with lived experience told us that the issues experienced in adulthood following preterm birth can be "subtle but multiple".[75] The Adult Preemie Advocacy Network noted that common "areas of challenge

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69 Victoria Coathup et al, 'Gestational age and hospital admissions during childhood: population based, record linkage study in England (TIGAR study)', *British Medical Journal*, vol. 371 (2020): https://www.bmj.com/content/371/bmj.m4075 [accessed 12 July 2024]

70 Katriina Heikkilä et al, 'Preterm birth and the risk of multimorbidity in adolescence: a multiregister-based cohort study', *The Lancet*, vol 8, issue 9, E680–E690: https://www.thelancet.com/journals/lanpub/article/PIIS2468-2667(23)00145-7/fulltext [accessed 12 July 2024]

71 Q 69 (Prof David Edwards)

72 Written evidence from Prof Samantha Johnson and Prof Neil Marlow (PRT0018)

73 Written evidence from Prof Maria Quigley (PRT0059) and British Association for Neonatal Neurodevelopmental Follow-Up (PRT0070)

74 Written evidence from Prof Dieter Wolke (PRT0010)

75 Written evidence from Gillian Ingledow (PRT0012)

and difficulty" reported by its members—adults who were born preterm and parents of preterm children—include physical and mental health, neurodivergence, experiences within education, relationships and employment.[76] Limited awareness within the healthcare system of the longer-term impacts of prematurity means informed or specialist support can be difficult to access.[77]

34. Evidence to the Committee underlined that the risk of adverse impacts following preterm birth is higher the earlier a baby is born.[78] Professor Elaine Boyle, Professor of Neonatal Medicine and Leicester City Football Club Professor in Child Health at the University of Leicester, emphasised, however, that there are "measurable adverse effects of being born before full term … even right up to 37 to 38 weeks".[79] We were also reminded that the number of babies born between 34 and 37 weeks is far higher than the number born extremely or very preterm, meaning many babies "are potentially vulnerable to the effects of mild to moderate prematurity".[80]

35. Prof Boyle suggested that gestational age should be viewed as "much more of a continuum or spectrum" when considering its impact on long-term outcomes.[81] Professor Jan van der Meulen, Professor of Clinical Epidemiology at the London School of Hygiene and Tropical Medicine, and Chair, National Maternity and Perinatal Audit Project Team, argued that treating gestational age at birth as "a dichotomy between being preterm and full term … underestimates the complexity of the problem that we are dealing with".[82]

36. We heard too that while advances in obstetric and neonatal care have led to improved survival rates for babies born prematurely, there has not been a corresponding improvement in neurodevelopmental outcomes.[83] As Prof Wolke explained:

> "Improved survival with no reduction in impairment and decreasing quality of life in the more recent cohorts indicates that more children born very or extremely preterm will require care in the future".[84]

Impact on parents and families

37. Preterm labour is "often sudden and traumatic"[85] and parents may have limited awareness of what this could mean for them and their baby.[86] Survey data from Tommy's suggested that nearly three-quarters of parents whose babies were born preterm "felt that they did not really understand what was happening to them."[87]

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76 Written evidence from Adult Preemie Advocacy Network (PRT0066)
77 Written evidence from Anonymous (PRT0002), Gillian Ingledow (PRT0012) and Anonymous (PRT0014)
78 Q 9, (Prof Jan van der Meulen) Q 69, (Prof Chris Gale) and Q 108 (Prof Elaine Boyle); Written evidence from Prof Samantha Johnson and Prof Neil Marlow (PRT0018)
79 Q 108 (Prof Elaine Boyle)
80 Written evidence from Prof Maria Quigley (PRT0059)
81 Q 108 (Prof Elaine Boyle)
82 Q 10 (Prof Jan van der Meulen)
83 Q 58 (Catriona Ogilvy); Written evidence from Prof Samantha Johnson and Prof Neil Marlow (PRT0018) and Neonatal Leads for Psychological Practice in England (PRT0052)
84 Written evidence from Prof Dieter Wolke (PRT0010)
85 Written evidence from The Smallest Things (PRT0032)
86 Written evidence from Spoons Charity (PRT0021), Abigail Mason-Woods (PRT0026) and Parent Advisory Group for the East of England Neonatal Operational Delivery Network (PRT0050)
87 Q 19 (Kath Abrahams)

38. Following a preterm birth, many parents will spend weeks or months caring for their baby in a neonatal unit. NHS guidance stresses that this is an "alien environment" which places parents "at significant risk of psychological and mental health difficulties". Being physically separated from their baby, feeling unsure of their role in the hospital context, and continued fear for their baby's wellbeing or survival can lead to trauma that is not "one-off" but "experienced repeatedly".[88]

39. This was echoed in the personal accounts shared by Nadia Leake and Francesca Segal, both mothers whose children required critical care following spontaneous preterm labour.[89] Ms Segal spoke of "the fundamentally unnatural separation of a post-partum mother from her babies", telling us that leaving her children at the neonatal unit each day "felt like a daily amputation".[90]

40. Witnesses with lived experience also emphasised the practical and financial challenges parents face in this period. They described how their preterm babies were cared for in multiple hospitals, sometimes at a significant distance from their home address.[91] One told us that they accrued accommodation, parking and subsistence costs totalling more than £9,000 over the multiple weeks of treatment their baby required.[92] The charity Bliss found that having a baby on a neonatal unit leads to average additional costs of £405 per week, and that one in four families have to borrow money or increase their debt to manage.[93]

41. The Smallest Things, a charity supporting families of preterm babies, described the experience of neonatal critical care as "an agonising journey of separation, anxiety and uncertainty". It stated that 24% of parents of preterm babies it surveyed had been diagnosed with post-traumatic stress disorder following discharge.[94] A separate study referenced in evidence to the Committee found that at discharge, "20% of mothers had clinically significant levels of depression, with 43% having moderate to severe anxiety."[95]

42. The charity Spoons said that the impact of neonatal care on parents' mental health "cannot be underestimated". It highlighted that parents may "struggle to feel like a parent" or to bond with their baby during this time.[96] Neonatal Leads for Psychological Practice in England told us that:

> "The impact on parental mental health has long been recognised to have a subsequent impact on the quality of attachment relationships between parents and their infants."[97]

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88 NHS, *Supporting mental healthcare in a maternity and neonatal setting* (July 2021), pp 51–52: https://www.england.nhs.uk/wp-content/uploads/2021/08/B0233-Health-in-Maternity-and-Neonatal-Settings-including-Neonatal-Loss-July-2021.pdf [accessed 12 July 2024]
89 Q 207 (Nadia Leake) and Q 210 (Francesca Segal)
90 Q 207 (Francesca Segal)
91 The availability of accommodation for parents in neonatal units is discussed in paras 159–62. QQ 209–210 (Nadia Leake, Francesca Segal); Written evidence from Anonymous (PRT0007) and Abigail Mason-Woods (PRT0026)
92 Written evidence from Anonymous (PRT0007)
93 Written evidence from Bliss (PRT0063)
94 Written evidence from The Smallest Things (PRT0032)
95 Written evidence from Neonatal Leads for Psychological Practice in England (PRT0052)
96 Written evidence from Spoons Charity (PRT0021)
97 Written evidence from Neonatal Leads for Psychological Practice in England (PRT0052)

43. Indeed, many witnesses echoed the statement made by Catriona Ogilvy, Founder and Chair of The Smallest Things, that "the journey does not end in the first few months or years after bringing a baby home from hospital".[98] Parents may not experience the full psychological impact of preterm birth and neonatal intensive care until months, or even years, later.[99] We heard that mental health issues can recur in relation to subsequent events, such as a preterm infant's first birthday, hospital readmissions or later pregnancies.[100] For some, the "heightened anxiety" resulting from a previous preterm birth "impacted their decision to have another child."[101] Overall, the impact of preterm birth can "pervade the wider family system, impacting on the experiences of siblings, couple and wider family relationships and the ways in which families develop and relate to each other".[102]

44. Many parents continue to encounter practical challenges, for example when trying to secure appropriate, informed educational or healthcare support for their child. Witnesses reported that such issues can persist even once their child has entered adulthood.[103] In some cases, children who were born prematurely "will need lifelong care and support" from their parents. This may mean that "parents are not able to go to work and contribute to society as they would have done".[104]

45. Professor Anna David, Professor in Obstetrics and Maternal Fetal Medicine at University College London, stressed that preterm birth "does not just affect the baby"; it also has wider health impacts for mother. She noted increased longer-term risks in relation to cancer, dementia and cardiovascular health.[105] A 2020 cohort study conducted in Sweden found that preterm and early term delivery were independent risk factors for premature mortality among women from several major causes, including diabetes and cancer. While these risks declined over time, they remained significantly raised up to 40 years later.[106] Kath Abrahams, Chief Executive, Tommy's, added that a preterm delivery can lead to an increased likelihood of miscarriage and repeat preterm birth in future pregnancies.[107]

The economic cost of preterm birth

46. Mr Badcock noted that, if a preterm infant has long-term care needs, this also represents a demand on Government services.[108] A number of studies have

98 Q 53 (Catriona Ogilvy)
99 Q 210 (Francesca Segal); Written evidence from Anonymous (PRT0009), The Smallest Things (PRT0032) and Parent Advisory Group for the East of England Neonatal Operational Delivery Network (PRT0050)
100 Q 207 (Nadia Leake); Written evidence from Katherine Sabin and Dr Fiona Challacombe (PRT0058)
101 Written evidence from Katherine Sabin and Dr Fiona Challacombe (PRT0058)
102 Written evidence from Neonatal Leads for Psychological Practice in England (PRT0052)
103 Q 211 (Francesca Segal); Written evidence from Gillian Ingledow (PRT0012), Dr Rachel Collum and Lady Sarra Hoy (PRT0031) and Katherine Sabin and Dr Fiona Challacombe (PRT0058)
104 Q 19 (David Badcock)
105 Q 66 (Prof Anna David)
106 Victoria Coathup et al, ' Gestational age and hospital admissions during childhood: population based, record linkage study in England', *British Medical Journal*, issue 8257 (2020): https://www.bmj.com/content/371/bmj.m4075 [accessed 12 July 2024]
107 Q 19 (Kath Abrahams)
108 Q 19 (David Badcock)

examined the economic consequences of preterm birth for the public sector.[109] Professor Stavros Petrou, Professor of Health Economics at the University of Oxford, highlighted modelling that suggests that the cost of preterm birth, for an annual cohort of children born in England and Wales, equates to £4.18 billion in current prices.[110] For an individual child, the additional cost associated with being born preterm is approximately £38,000, rising to more than £134,000 for extremely preterm infants.[111]

47. Prof Petrou explained that neonatal care following a preterm baby's initial hospitalisation makes up the bulk of the overall cost. By the 11th year of childhood, however, ongoing costs to the healthcare system are "dwarfed" by "costs associated with special educational needs".[112] Describing the annual cost of preterm birth to Australia, Professor John Newnham, Professor of Obstetrics and Gynaecology at the University of Western Australia, and Chair, Australian Preterm Birth Prevention Alliance, similarly noted that "one in four dollars is borne by the education department, not by the ministry for health".[113]

48. Prof Newnham also stated that a reduction in the rate of preterm birth in Australia from 8.7% to 8.2% had resulted in annual government cost savings of AUS$90 million.[114] Economic modelling for England and Wales has suggested that delaying preterm births by a week, across the gestational ages, would lead to cost savings of £1.41 billion per year.[115] BAPM argued that "investment in simple low-cost interventions" that would improve outcomes for babies when preterm birth does occur "will engender longitudinal cost savings within healthcare and education many times over."[116]

The national ambition to reduce preterm birth

Progress towards the maternity safety ambition

49. The Department of Health and Social Care (DHSC) told the Committee that "good progress" has been made on some aspects of the national maternity safety ambition. It stated that, since 2010, the incidence of stillbirth has fallen by 23%, and the neonatal death rate by 30%. The proportion of babies born preterm saw "a slower reduction", however, decreasing from 8.0% in 2017 to 7.7% in 2021.[117] In 2022, the rate increased to 7.9%.[118]

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109 See, for example, Lindsay J. Mangham et al, *The Cost of Preterm Birth Throughout Childhood in England and Wales*; Miaoqing Yang et al, 'Neonatal health care costs of very preterm babies in England: a retrospective analysis of a national birth cohort', *BMJ Paediatrics Open*, vol. 7, (2023): https://bmjpaedsopen.bmj.com/content/7/1/e001818 [accessed 2 September 2024]; and Xinyang Hua et al, 'Gestational age and hospital admission costs from birth to childhood: a population-based record linkage study in England', *Archives of Disease in Childhood—Fetal and Neonatal Edition*, vol. 108, (2023): https://fn.bmj.com/content/108/5/485 [accessed 12 July 2024]

110 Q 109 (Prof Stavros Petrou)

111 Q 111 (Prof Stavros Petrou)

112 Q 110 (Prof Stavros Petrou)

113 Q 204 (Prof John Newnham)

114 Q 196 (Prof John Newnham)

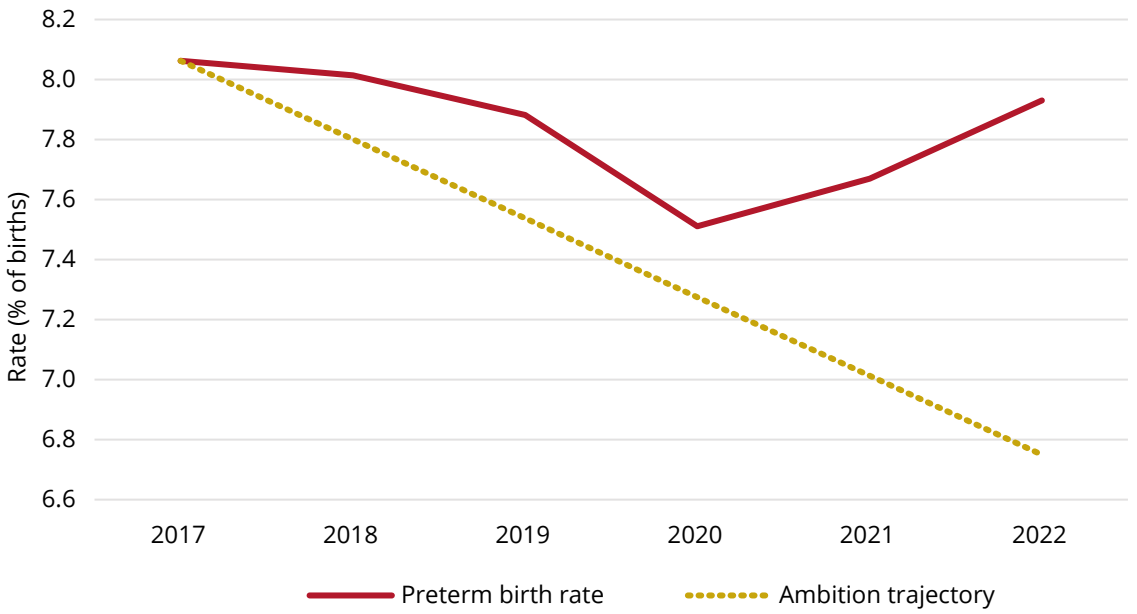
115 Q 109 (Prof Stavros Petrou)

116 Written evidence from British Association of Perinatal Medicine (PRT0042)

117 Written evidence from Department of Health and Social Care (PRT0081)

118 See para 3 and Table 1. Data available at: ONS, 'Birth Characteristics in England and Wales: 2022': https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/bulletins/birthcharacteristicsinenglandandwales/2022#births-data [accessed 8 July 2024]

Figure 1: Preterm birth rates in England between 2017 and 2022 and trajectory required to meet 2025 target



Source: ONS, 'Birth characteristics in England and Wales: 2022': https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/livebirths/datasets/birthcharacteristicsinenglandandwales [accessed 15 July 2024]

50. Professor Marian Knight MBE, Professor of Maternal and Child Population Health and Director of the National Perinatal Epidemiology Unit, told us: "If you look back at the data … there has been no progress since 2016".[119] The Sands and Tommy's JPU agreed, concluding that we are "not on track" to meet the 6% ambition.[120] The Royal College of Obstetricians and Gynaecologists (RCOG) suggested that the ambition "is a reasonable goal, but the timescale is likely now to be unrealistic".[121]

51. Professor Donald Peebles, National Clinical Director for Maternity at NHS England, acknowledged that the rate "has clearly gone up" in recent years, despite declining previously. He added: "Our best evidence would be that it has gone up again this year". He stated that "there is no way" that the ambition to reach 6% by 2025 will be achieved.[122] Baroness Merron, Parliamentary Under-Secretary of State for Patient Safety, Women's Health and Mental Health, commented:

> "I see that this ambition is not going to be met. I understand that it has provided a focus, but a focus is not only what we need; we need to achieve."[123]

119 Q 2 (Prof Marian Knight MBE)
120 Written evidence from Sands and Tommy's Joint Policy Unit (PRT0045)
121 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
122 Q 245 (Prof Donald Peebles)
123 Q 255 (Baroness Merron)

Inequalities in preterm birth incidence and outcomes

52. The inequalities in preterm birth rates and outcomes that exist between different groups of the population were raised consistently by witnesses.[124] Sam Pretlove, Deputy Chief Medical Officer at Birmingham Women's and Children's NHS Foundation Trust, explained that in her integrated care board (ICB),

> "76 babies are born prematurely per year due to health inequalities. If everyone in Birmingham had the same risk as a white woman in the least deprived quintile, there would be 76 fewer babies born preterm."[125]

53. A 2021 cohort study based on data from NHS hospitals across England found that socioeconomic and ethnic inequalities "were responsible for a substantial proportion" of preterm births in England. It determined that the risk of preterm birth was 4.9% among women in the least deprived socioeconomic group, compared to 7.2% in the most deprived group. Overall, the study estimated that approximately 18.5% of preterm live births "could be attributed to socioeconomic inequality", although this figure reduced to 11.9% when adjusted for ethnic group, smoking status and body mass index.[126]

54. We heard from Sands and Tommy's JPU that:

> "In 2021, the proportion of preterm births out of total live births was highest among Black babies (8.7%) in England and Wales. This rate has remained consistently above all other ethnic groups since at least 2010 … In the same year, preterm births were second highest among Asian babies (8.1%)".

55. Dr Jennifer Jardine, Academic Clinical Lecturer in Obstetrics and Gynaecology at Queen Mary University of London, suggested that the difference in preterm birth rates between ethnic groups "is probably accounted for by socioeconomic deprivation".[127] However, Tommy's argued: "Even after adjusting for the level of deprivation, differences in preterm birth across ethnic groups remain."[128] Sam Pretlove told us that "ethnicity has seemed to function as an independent variable to social deprivation" in data from her ICB.[129]

56. A 2021 report from the National Maternity and Perinatal Audit stated that Black women were also more than twice as likely (0.9%) to give birth to an extremely preterm baby than White women (0.4%).[130] The Sands and Tommy's JPU noted that the proportion of babies born both extremely and very preterm was higher among Black ethnic groups. It stressed that "this

124 Q 4 (Prof Jan van der Meulen), Q 26 (Kath Abrahams) and Q 58 (Caroline Lee-Davey); Written evidence from British Maternal and Fetal Medicine Society (PRT0008), CLOSER (UCL) (PRT0023), Tommy's (PRT0057) and Bliss (PRT0063)

125 Q 217 (Sam Pretlove)

126 Jennifer Jardine et al., 'Adverse pregnancy outcomes attributable to socioeconomic and ethnic inequalities in England: a national cohort study' *The Lancet*, vol. 398, (2021): https://www.thelancet.com/journals/lancet/article/PIIS0140-6736(21)01595-6/fulltext [accessed 12 July 2024]

127 Q 12 (Dr Jennifer Jardine)

128 Written evidence from Tommy's (PRT0057)

129 Q 218 (Sam Pretlove)

130 Kirstin Webster and National Maternity and Perinatal Audit (NMPA) Project Team, *Ethnic and Socioeconomic Inequalities in NHS Maternity and Perinatal Care for Women and their Babies: Assessing care using data from births between 1 April 2015 and 31 March 2018 across England, Scotland and Wales* (2021): https://maternityaudit.org.uk/FilesUploaded/Ref%20308%20Inequalities%20Sprint%20Audit%20Report%202021_FINAL.pdf [accessed 12 July 2024]

difference is important due to the substantially higher mortality rates at lower gestational ages."[131]

57. NCMD reported that mothers from Asian and Asian British families face around a 60% increase in the chance of their baby dying from preterm birth by the age of one, compared to mothers from White backgrounds. For Black and Black British mothers, there is over a two-fold increase in risk. Again, "this association persisted, and indeed, barely changed, even after taking into account the local levels of deprivation the families lived in". NCMD also noted that deaths from prematurity have increased over the last four years, with these increases "seen exclusively in children from non-White minority ethnic groups … and in the most deprived areas".[132]

Updating the maternity safety ambition targets

58. In its latest monitoring report, the Sands and Tommy's JPU called for "renewed commitments beyond 2025". It stated that these should include "an ambition to address inequalities".[133] Tommy's noted that there are currently "no national targets or long-term funding to reduce inequalities between ethnic groups or areas of deprivation". This is despite the fact that achieving the target of a 6% preterm birth rate "would require much larger reductions among some groups" of the population.[134]

59. RCOG likewise urged "the adoption of a target to drive a reduction in socioeconomic and ethnic inequalities in maternity care".[135] Bliss argued:

> "The Government should commit to clear targets to reduce inequalities in the rates of neonatal death, brain injury and preterm birth across socioeconomic and ethnic groups and between neonatal units".[136]

60. On an overarching target to reduce the rate of preterm birth, we were reminded that "preterm birth is an outcome of many different processes and heterogenous systems".[137] Kate Brintworth, Chief Midwifery Officer at NHS England, argued: "it is a very complicated picture. You cannot just apply one crude measure or intervention to make it improve."[138]

61. Prof Peebles described the current target as "a very big catch-all" that "covers a very wide range of gestations". The causes of prematurity differ according to gestational age, so "you could make improvements in one bit and not in another".[139] Dr Jardine felt that "aiming at this target of 6% … masks all sorts of changes", making it harder to "understand where improvements are happening". She added: "it is quite difficult for people to keep on delivering interventions and then to see that the number overall stays the same".[140]

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131 Written evidence from Sands and Tommy's Joint Policy Unit (PRT0045)
132 Written evidence from National Child Mortality Database (PRT0060)
133 Sands and Tommy's Joint Policy Unit, *Saving Babies' Lives 2024: A report on progress* (May 2024), p 7: https://www.tommys.org/sites/default/files/2024–05/Embargoed%20-%20Saving%20babies%27%20lives%20progress%20report%202024_final.pdf [accessed 12 July 2024]
134 Written evidence from Tommy's (PRT0057)
135 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
136 Written evidence from Bliss (PRT0063)
137 Q 15 (Dr Jennifer Jardine)
138 Q 245 (Kate Brintworth)
139 Q 245 (Prof Donald Peebles)
140 Q 15 (Dr Jennifer Jardine)

62. The National Institute for Health and Care Research (NIHR) Children and Families Policy Research Unit highlighted that preterm birth rates "may increase because of interventions to reduce other unfavourable pregnancy outcomes", such as stillbirth.[141] Prof Peebles made a similar point and stated that intervention rates have indeed risen.[142] Professor Lucy Chappell, Chief Executive Officer at NIHR and Chief Scientific Adviser at DHSC, set out that, according to recent data, approximately 50% of preterm births are provider initiated.[143]

63. Witnesses drew particular attention to this distinction between spontaneous preterm labour and a planned preterm delivery, noting that the latter "is frequently life-saving".[144] The NIHR Children and Families Policy Research Unit felt, therefore, that when monitoring preterm birth rates "it is important to take into account whether preterm births occurred spontaneously or as a result of medical intervention."[145] Prof Jan van der Meulen agreed.[146] RCOG concluded, however, that "on the whole, a focus on preterm birth is acceptable", since "reducing the incidence of many of the causes of iatrogenic preterm birth is also positive".[147]

64. RCOG went on to say that an additional target focused on reducing the morbidity associated with preterm birth warrants consideration.[148] BAPM similarly argued that this area deserves a "national focus, with identified goals". An ambition of this kind should "target specific rates of decrease in the overall rate of preterm mortality, as well as in the variation in preterm mortality observed within the UK"; and seek to "reduce preterm brain injury, and the observed variation, again identifying specific targets".[149]

65. When asked whether the new Government would introduce revised targets that go beyond 2025, Baroness Merron told us: "We will certainly be looking at a new ambition, but I am really keen … to make sure it is workable". She acknowledged that the current target for preterm birth is "a blunt instrument" for measuring improvements. She proposed that the new ambition should be "more sensitive" and "one that focuses on prevention and outcome".[150]

66. **We heard stark evidence about the impact of preterm birth. It is a major contributor to neonatal mortality and morbidity, and can lead to significant, and often lifelong, adverse consequences for individuals born preterm. Neonatal care following a preterm birth is often a traumatic experience, and its impact on parents and families can endure long after discharge from hospital.**

67. **A co-ordinated effort to reduce the incidence of preterm birth and mitigate its negative consequences is therefore vital. As well as improving outcomes for babies and their families, there is a clear economic case for this; reducing the immediate and longer-term**

141 Written evidence from NIHR Children and Families Policy Research Unit (PRT0034)
142 Q 247 (Prof Donald Peebles)
143 Q 255 (Prof Lucy Chappell)
144 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
145 Written evidence from NIHR Children and Families Policy Research Unit (PRT0034)
146 Q 14 (Prof Jan van der Meulen)
147 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
148 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
149 Written evidence from British Association of Perinatal Medicine (PRT0042)
150 QQ 255–6 (Baroness Merron)

impacts of preterm birth could generate substantial cost savings within healthcare and education.

68. **We welcome that the current maternity safety ambition recognises the importance of lowering the rate of preterm birth. It is clear, however, that the target to reduce the rate to 6% by 2025 will not be met. We are persuaded that a more nuanced target, or set of targets, would be more effective in enabling improvements to be monitored. A metric focused on addressing the disparities in preterm birth rates and outcomes across different socioeconomic and ethnic groups deserves particular consideration.**

69. ***In its response to this report, the Government should set out its plans to revise the current national maternity safety ambition, focusing particularly on targets that will support efforts to reduce the incidence and impact of preterm birth.***

CHAPTER 3: RISK FACTORS AND PREVENTION

Risk factors for preterm birth

70. Evidence to the Committee set out that preterm birth "is a complex, multifactorial disorder with biological, environmental and social determinants."[151] Most women who go on to give birth preterm have no apparent risk factors and, in many cases, it is not clear why a preterm birth occurred.[152] There are, however, a wide range of factors that are associated with a higher likelihood of delivering early.

Pregnancy-related factors

71. Issues that arise during pregnancy that can lead to increased risk include, for example, preterm prelabour rupture of membranes (PPROM), pre-eclampsia and fetal growth restriction. If the cervix shortens during pregnancy, this can also represent a greater risk.[153] These factors can increase the likelihood of provider initiated, as well as spontaneous, preterm labour.[154]

Box 2: Preterm prelabour rupture of membranes (PPROM)

PPROM refers to when the membrane containing the amniotic fluid surrounding the baby ruptures (also known as waters breaking) before labour at less than 37 weeks of pregnancy. This can happen in up to 3% of pregnant women but is associated with three to four of every 10 preterm births. About 50% of women with PPROM will go into labour within the first week after their waters break. This is more likely the further along a woman is in pregnancy. Following PPROM, there is an increased risk of infection in the uterus. If the mother or baby develop signs of infection, provider initiated preterm labour may be felt to be necessary, to avoid further complications.

Source: Royal College of Obstetricians and Gynaecologists, 'When your waters break prematurely' (June 2019):, https://www.rcog.org.uk/for-the-public/browse-our-patient-information/when-your-waters-break-prematurely/ [accessed 10 July 2024]

72. Women having a multiple birth are significantly more likely to give birth preterm: 55–60% of twins are born preterm compared to 6–6.5% of singletons.[155] Professor Asma Khalil, Professor of Obstetrics and Maternal Fetal Medicine at St George's Hospital, University of London, suggested that in vitro fertilisation (IVF) contributes to an increased number of multiple pregnancies, and therefore preterm births.[156] The Human Fertilisation and Embryology Authority (HFEA) argued, however, that the impact of IVF has significantly reduced in recent years, with the rate of multiple birth following

151 Written evidence from Tommy's (PRT0057)
152 Written evidence from Tommy's (PRT0057) and Royal College of Obstetricians and Gynaecologists (PRT0072)
153 Written evidence from UK National Screening Committee (PRT0004) and Tommy's (PRT0057); Royal College of Obstetricians and Gynaecologists, 'Care of Women Presenting with Suspected Preterm Prelabour Rupture of Membranes from 24+0 Weeks of Gestation (Green-top Guideline No. 73)': https://www.rcog.org.uk/guidance/browse-all-guidance/green-top-guidelines/care-of-women-presenting-with-suspected-preterm-prelabour-rupture-of-membranes-from-24plus0-weeks-of-gestation-green-top-guideline-no-73/ [accessed 22 October 2024]
154 Q 4 (Dr Jennifer Jardine); Written evidence from Suffolk and Northeast Essex Local Maternity and Neonatal System (PRT0080); Tommy's, 'Causes of Premature Birth': https://www.tommys.org/pregnancy-information/premature-birth/causes-of-premature-birth [accessed 5 July 2024]
155 Q 3 (Dr Jennifer Jardine); Written evidence from Suffolk and Northeast Essex Local Maternity and Neonatal System (PRT0080)
156 Q 49 (Prof Asma Khalil)

IVF falling from 28% in the 1990s to 5% in 2021.[157] HFEA also reported that, from 2015 to 2019, around 60% of IVF live twin births were preterm. For IVF singleton pregnancies, the rate was 9%.[158]

73. We also heard that "many risk factors for preterm birth are dependent on what has happened in a previous pregnancy".[159] Factors detailed in the Saving Babies' Lives Care Bundle (SBLCB) as indicating a high risk of preterm birth include previous preterm or mid-trimester loss and previous PPROM.[160] Dr Jennifer Jardine, Academic Clinical Lecturer in Obstetrics and Gynaecology at Queen Mary University of London, told us that whether a woman has had a previous preterm birth is the "biggest predictor on an individual level".[161]

Wider health and social factors

74. Evidence to the Committee emphasised that health conditions that exist prior to pregnancy, such as diabetes, hypertension and mental health problems, can increase a woman's risk of preterm birth.[162] Having a body mass index (BMI) of under 18 or over 35 was another risk factor that was highlighted.[163] We also heard that preterm birth is more prevalent among women at the lower and upper ranges of maternal reproductive age.[164]

75. Action on Smoking and Health stated that smoking during pregnancy increases the risk of preterm birth by 27%.[165] The measures proposed by the Government's Tobacco and Vapes Bill[166] aim to reduce smoking prevalence to 0%. The impact assessment for the bill noted the potential for consequential improvements in pregnancy outcomes, citing evidence that:

> "Women who smoked during pregnancy were 2.6 times more likely to give birth prematurely. These babies were more likely to have a lower birth weight and were 4.1 times more likely to be small-for-date babies."[167]

76. Researchers from the School of Public Health at Imperial College London and the Erasmus MC Sophia children's hospital in Rotterdam noted that for women exposed to second-hand tobacco smoke, the preterm birth risk may be "up to 2.5 times higher" than for non-exposed women. They added: "Antenatal tobacco smoke exposure is also linked to poorer developmental and health outcomes among those born preterm."[168] Other lifestyle

157 HFEA note that this was achieved following the "One at a time" campaign, launched in 2007. It added that, despite this progress, there are a small number of clinics that still have high multiple birth rates. It called for HFEA to have a "broader and more proportionate range of regulatory enforcement powers" to tackle this. Written evidence from Human Fertilisation and Embryology Authority (PRT0084)
158 Written evidence from Human Fertilisation and Embryology Authority (PRT0084)
159 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
160 NHS England, *Saving Babies' Lives Version Three*
161 Q 12 (Dr Jennifer Jardine)
162 Q 4 (Prof Jan van der Meulen); Written evidence from UK National Screening Committee (PRT0004) and ESMI II Research Team (PRT0071)
163 Q 167 (Prof Andrew Shennan OBE); Written evidence from Suffolk and Northeast Essex Local Maternity and Neonatal System (PRT0080)
164 Q 4 (Prof Jan van der Meulen); Written evidence from Suffolk and Northeast Essex Local Maternity and Neonatal System (PRT0080)
165 Written evidence from Action on Smoking and Health (PRT0077)
166 Tobacco and Vapes Bill [Bill 121 (2024–25)]
167 Impact Assessment to the Tobacco and Vapes Bill [Bill 121 (2024–25)-IA]
168 Written evidence from Prof Christopher Millett, Dr Jasper Been, Dr Filippos Filippidis, Dr Anthony Laverty and Ruth Goh (PRT0033)

behaviours associated with an increased risk of preterm birth include alcohol consumption and drug use during pregnancy.[169]

77. As previously noted, women from some ethnic minority backgrounds and those from poorer households are more likely to give birth preterm.[170] Tommy's told us that the reasons for these inequalities in risk are "complex and interrelated". It posited: "Explanations include differences in access to and treatment by maternity services, health behaviours, and personal and social contexts."[171]

78. Other witnesses raised similar points, highlighting factors such as differences in smoking rates, BMI and job security.[172] On access to maternity care, Sam Pretlove noted that in her ICB, fewer than 50% of Black African women book their initial pregnancy appointment before 10 weeks, as is recommended, and "many book markedly later than that." She explained: "That is a real problem, because you then lose the ability to do your preterm birth interventions, which start at 16 weeks."[173] Catherine McClennan reported feedback from women in more deprived areas of her ICB that "it is a choice between feeding their children that day and whether they can afford their bus fare" to attend maternity appointments.[174]

79. Witnesses acknowledged the challenge of determining causality for these kinds of risk factors. They argued, however, that there is strong evidence to indicate association between preterm birth and some of the risk factors discussed above, particularly smoking, socioeconomic deprivation and pre-existing health conditions including diabetes.[175] One LMNS attributed a recent decrease in local preterm birth rates as being "predominantly due to" the introduction of a smokefree pregnancy pathway. It predicted that "the next significant impact" in reducing incidence would be provided by services focused on primary prevention and preconception health.[176]

Interventions to prevent preterm birth

Current policies and guidance

80. In view of the wide range of risk factors associated with preterm birth, guidance on prevention in the SBLCB focuses on three main areas:

- reducing the risk of a preterm birth occurring by improving women's overall health during pregnancy, for example by supporting women to stop smoking;
- universal screening for risk factors related to preterm birth; and

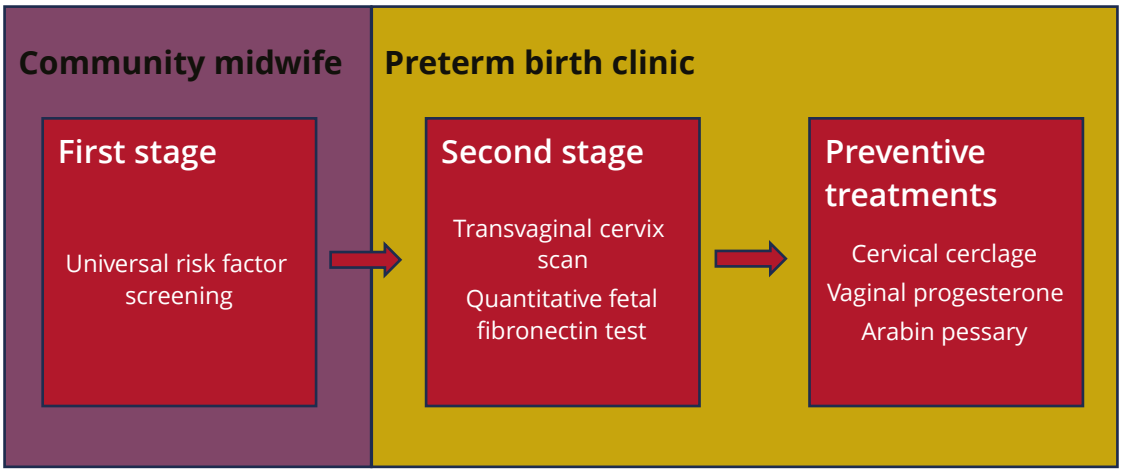
169 Q 167 (Prof Andrew Shennan OBE); Tommy's, 'Causes of Premature Birth': https://www.tommys.org/pregnancy-information/premature-birth/causes-of-premature-birth [accessed 5 July 2024]
170 See paras 52–55.
171 Written evidence from Tommy's (PRT0057)
172 Q 4 (Prof Jan van der Meulen) and Q 12 (Dr Jennifer Jardine); Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
173 Q 219 (Sam Pretlove)
174 Q 219 (Catherine McClennan)
175 Q 5 (Prof Marian Knight MBE), Q 8 (Prof van der Meulen), Q 167 (Prof Judith Stephenson, Prof Andrew Shennan OBE)
176 Written evidence from Suffolk and Northeast Essex Local Maternity and Neonatal System (PRT0080)

- for those shown to be at increased risk, referral to "a care pathway designed to reduce the chances of preterm birth" via targeted interventions delivered by specialist clinics.[177]

81. Initial screening is conducted by a community midwife as part of the antenatal booking appointment, which should take place when a woman is between eight and 12 weeks pregnant.[178] Any woman identified as being at intermediate or high risk of having a preterm birth is then referred to a preterm birth clinic for the second stage of screening.[179]

82. The SBLCB outlines that, "as a minimum", this second stage should include a transvaginal scan to assess cervix length and sometimes a quantitative fetal fibronectin test,[180] depending on the woman's specific risk assessment.[181] Women may then be offered treatment to try to prevent preterm birth, such as cervical cerclage, Arabin pessary or vaginal progesterone.[182]

Figure 2: Screening and preventive treatments



83. The Department of Health and Social Care (DHSC) highlighted too the targeted provision of flu and COVID-19 vaccinations for pregnant women, and the rollout of maternal medicine networks, as interventions that could help to reduce the causes of provider-initiated preterm birth. The introduction of midwife continuity of carer[183] was also mentioned.[184]

Benefits and limitations

Screening

84. Prof Khalil highlighted that "the challenge" of the current two-step approach to screening is that most women who go on to give birth preterm do not have the risk factors that are assessed at the initial booking appointment.[185] We

177 Written evidence from the Department of Health and Social Care (PRT0081); NHS England, *Saving Babies' Lives Version Three*
178 Q 31 (Dr Catherine Aiken); Written evidence from the Department of Health and Social Care (PRT0081); NHS, 'Your antenatal appointments': https://www.nhs.uk/pregnancy/your-pregnancy-care/your-antenatal-appointments/ [accessed 2 September 2024]
179 Q 31 (Dr Catherine Aiken)
180 See glossary.
181 NHS England, *Saving Babies' Lives Version Three*
182 See glossary. NHS England, *Saving Babies' Lives Version Three*
183 See paras 142–43 and Box 5.
184 Written evidence from the Department of Health and Social Care (PRT0081)
185 Q 32 (Prof Asma Khalil)

heard too that, although many risk factors relate to previous pregnancies, preterm birth frequently occurs in a woman's first pregnancy, meaning there is "no obstetric history as a predictor".[186] The SBLCB itself sets out that there are "imperfections in the predictability of preterm birth on the basis of history".[187]

85. Prof Khalil also noted that the risk factors assessed at the initial booking "do not all have the same strength of association" with preterm birth. However, as the test relies on "almost a checklist approach", it does not allow for this.[188] Professor Basky Thilaganathan, spokesperson for the Royal College of Obstetricians and Gynaecologists and Clinical Director of the Tommy's National Centre for Maternity Improvement, commented that the checklist-based system does not take account of a women's ethnicity or level of socioeconomic deprivation; treats other risk factors as categorical rather than continuous; and places too great an emphasis on women who have had a previous preterm birth.[189] Overall, he felt that it "overidentifies women as being at high risk of preterm birth".[190] As a result, "we flood an inadequately staffed service with women who do not need to be seen."[191]

86. Prof Thilaganathan suggested that screening could be improved by adopting new technologies, in particular the Tommy's app.[192] Alongside pregnancy history data, the app requires inputs on factors including age, BMI, ethnicity, and smoking status. It produces a risk score for a number of pregnancy complications, including preterm birth.[193] Prof Thilaganathan also proposed that the QUiPP algorithm, which supports the assessment of women in suspected preterm labour,[194] could be used during or after the second screening by the specialist preterm birth clinic to predict more accurately which women will give birth preterm.[195]

87. The SBLCB makes reference to both of these tools, suggesting that they may be "useful to support assessment" and could "improve predictive accuracy of triage".[196] Prof Thilaganathan explained that evidence on the value of the Tommy's app from four early adopter sites is due to be published in 2025. The results of a further randomised control trial are expected to be available in 2027.[197]

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186 Written evidence from Suffolk and Northeast Essex Local Maternity and Neonatal System (PRT0080)
187 NHS England, *Saving Babies' Lives Version Three*
188 Q 32 (Prof Asma Khalil)
189 For example, a woman may be deemed to be at risk if she is 40 years old but not if she is 39 and 11 months. Q 183 (Prof Basky Thilaganathan)
190 Q 190 (Prof Basky Thilaganathan)
191 Q 183 (Prof Basky Thilaganathan)
192 *Ibid.*
193 Sands and Tommy's Joint Policy Unit, *Saving Babies' Lives 2023* (May 2023): https://www.sands.org.uk/sites/default/files/JPU_Saving_Babies_Lives_Report_2023.pdf; [accessed 10 July 2024] Tommy's, 'The Tommy's National Centre for Maternity Improvement: How are we transforming maternity care in the UK?': https://www.tommys.org/research/research-centres/tommys-national-centre-maternity-improvement/transforming-maternity-care [accessed 10 July 2024]
194 This forms the basis of the QUantitative Innovation in Predicting Preterm birth (QUiPP) app, a clinical decision-making tool. It combines fetal fibronectin values, cervical length measurements and clinical history regarding risk factors for preterm birth to calculate an individualised percentage risk of delivery. QUiPP, 'About': https://quipp.org/about [accessed 22 October 2024]
195 Q 190 (Prof Basky Thilaganathan)
196 NHS England, *Saving Babies' Lives Version Three*
197 Q 190 (Prof Basky Thilaganathan)

88. Dr Caroline Fox, writing on behalf of the PRE-EMPT study,[198] advocated offering a cervical length scan, currently used during the second stage of the screening process, to all women in their first pregnancy.[199] Professor Mark Johnson, Clinical Chair in Obstetrics at Imperial College London, explained that this approach has been introduced at King's College Hospital, with positive results.[200]

89. According to Dr Fox, cervical length screening "has been shown to be effective in reducing preterm birth in France, Greece, Israel, and Australia".[201] Professor John Newnham, Chair of the Australian Preterm Birth Prevention Alliance (APBPA) and Professor of Obstetrics and Gynaecology at the University of Western Australia, told us that measuring the length of the cervix at all mid-pregnancy ultrasound scans is one of the seven evidence-based strategies set out in the APBPA prevention programme.[202]

Box 3: The Australian Preterm Birth Prevention Alliance

The Australian Preterm Birth Prevention Alliance was established in 2018. It developed from a programme in Western Australia (The Whole Nine Months) which received federal government funding to enable it to be rolled out across the country.[203] Several clinical interventions are promoted to healthcare professionals, including routine cervical length scanning and referral to smoking cessation counselling.[204]

Prof Newnham told the Committee that the national programme has been coupled with "a massive education programme for the women and families of Australia". He reported that between 2018 and 2021, the preterm birth rate in Australia fell from 8.7% to 8.2%.[205]

90. Professor Sarah Stock, Professor of Maternal and Fetal Health at University of Edinburgh, told us, however, that only "10% of all preterm births are in women screened with a short cervix". She added that, in a low-risk population, only three in 10 women with a positive test would go on to give birth preterm. In her view, universal screening could lead to overtreatment and would not identify many of the women who do deliver early.[206]

91. Dr Fox and Prof Johnson acknowledged that further research is required to determine whether a cervical length scan should be offered to all women.[207] The Royal College of Obstetricians and Gynaecologists (RCOG) suggested that priorities for further research relating to screening were "options for population screening, why women and people in their first pregnancy have

198 The 'Preventing preterm birth in nulliparous women through cervical length screening' (PRE-EMPT) study is a proposed study to establish the acceptability and effectiveness of a cervical length screen for women in their first pregnancy, particularly women from Black, Asian and deprived backgrounds. Written evidence from Dr Caroline Fox (PRT0005)
199 Written evidence from Dr Caroline Fox (PRT0005)
200 Q 63 (Prof Mark Johnson)
201 Written evidence from Dr Caroline Fox (PRT0005)
202 Q 196 (Prof John Newnham)
203 Australian Preterm Birth Alliance, 'Our Story' https://pretermalliance.com.au/Our-cause/Our-story [accessed 23 July 2024]
204 Australian Preterm Birth Alliance, 'Clinical Guidelines' https://pretermalliance.com.au/Our-Research/Clinical-Guidelines [accessed 23 July 2024]
205 Q 196 (Prof John Newnham)
206 Q 63 (Prof Sarah Stock)
207 Q 63 (Prof Mark Johnson); Written evidence from Dr Caroline Fox (PRT0005)

preterm birth, and what the best predictive tests and treatments are for them."[208]

92. The latest review by the National Screening Committee (NSC),[209] carried out in 2020,[210] concluded that cervical length measurement and fetal fibronectin testing are "not useful at predicting preterm birth in asymptomatic low-risk women". NSC told us that studies to assess the effectiveness of these tests "found that fewer than half of women who had a high-risk result went on to have preterm birth". The tests also "picked up other women who went on to have a normal, full-term birth". NSC suggested that universal screening for preterm birth could "divert resources to healthy women" and away from those who are most at risk.[211]

Treatments

93. NSC also argued that more research is needed to determine the effectiveness of the treatments that are offered to women who are identified as being at high risk of giving birth prematurely. It suggested there was "some evidence" that vaginal progesterone may reduce the risk of preterm birth for women found to have a short cervix; that cervical cerclage "was not helpful in preventing preterm birth"; and that it was "not clear" whether a pessary "might help some women".[212]

94. The SBLCB states that:

> "At present the evidence base cannot determine precisely in which pregnant women, and in what circumstances, each intervention will be most effective."[213]

A survey completed by English maternity units in 2021 demonstrated that 19% of preterm birth clinics offered progesterone as a first-line therapy for women with short cervical length, 63% offered a cerclage and 22% offered a combined therapy.[214]

95. Dr Catherine Aiken, Associate Professor and Honorary Consultant in Fetal and Maternal Medicine at Cambridge University Hospitals, told us that all three interventions are "at least partially effective" for certain women; "the difficulty is disentangling the evidence to figure out exactly which woman should get which intervention."[215] Prof Johnson stated that clinicians have "no idea" how best to target treatments, or what dosage should be offered. He saw it as "unbelievable" that "fundamental facts" such as these are not yet known.[216]

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208 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
209 The NSC is part of the DHSC and is an independent committee that advises ministers and the NHS and supports implementation of screening programmes. Department of Health and Social Care, 'UK National Screening Committee': https://www.gov.uk/government/organisations/uk-national-screening-committee [accessed 5 July 2024]
210 UK National Screening Committee, 'Preterm Birth': https://view-health-screening-recommendations.service.gov.uk/preterm-birth/ [accessed 16 September 2024]
211 Written evidence from UK National Screening Committee (PRT0004)
212 *Ibid.*
213 NHS England, *Saving Babies' Lives Version Three*
214 British Medical Council, 'How are hospitals in England caring for women at risk of preterm birth in 2021? The influence of national guidance on preterm birth care in England: a national questionnaire': https://bmcpregnancychildbirth.biomedcentral.com/articles/10.1186/s12884–023-05388-w [accessed 10 July 2024]
215 Q 33 (Dr Catherine Aiken)
216 Q 67 (Prof Mark Johnson)

96. We heard that, underlying this, is a lack of understanding of the molecular mechanisms that trigger preterm and term labour.[217] Dr Aiken described this as "the elephant in the room":

> "The fact that we do not know in detail the molecular pathway that leads to the onset of normal labour and delivery is way below the standard that you would expect in most fields of medicine."[218]

She argued that there are therefore "very few targets to intervene on" to predict or prevent preterm birth.[219]

97. Professor David MacIntyre, Professor of Reproductive Systems Medicine at Imperial College London, set out that an improved understanding of the mechanisms would enable existing treatments to be given in a more targeted way. It would also support the identification of "better biomarkers and screening procedures that we can employ earlier in pregnancy."[220]

Perinatal optimisation

98. The SBLCB recommends a range of perinatal optimisation interventions[221] that may be offered to women who are identified as being at risk of preterm birth. These include making women aware of the symptoms of preterm labour and ensuring "there is time to meet as a perinatal team to discuss care options with parents prior to birth."[222]

99. RCOG recommended that women who are identified as being at high risk should also be provided with antenatal psychological support, describing this as an "unmet need" at present.[223] Witnesses with lived experience called for more information on preterm birth and neonatal care, including conditions such as PPROM, to be made available to parents during pregnancy. We heard that this would empower parents to recognise symptoms and advocate for the right treatment and support.[224] While acknowledging that such information must be "proportionate and appropriate", one mother argued that concerns about distressing parents were miscalculated: "In fact, not knowing enough about preterm birth antenatally traumatised me when I found myself experiencing it."[225]

100. **A woman's individual risk of giving birth preterm is determined by a complex set of interrelated factors. Predicting and preventing preterm birth is therefore challenging. While the Committee heard that screening and the targeting of treatment could be improved, further research is required to understand the biological mechanisms**

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217 Q 46 (Dr Catherine Aiken) and QQ 64–67 (Prof Mark Johnson, Prof David MacIntyre, Prof Sarah Stock). This is discussed further in Chapter 6.
218 Q 46 (Dr Catherine Aiken)
219 *Ibid.*
220 Q 67 (Prof David MacIntyre)
221 These are intended to improve outcomes for preterm babies when preterm labour is planned, suspected or confirmed. They are implemented shortly before and after birth. They include transferring the mother to a hospital with a NICU; offering corticosteroid injections to support the baby's brain and lung development; and providing babies born prematurely with early maternal breast milk, ideally within six hours of birth. Written evidence from Tommy's (PRT0057); NHS England, *Saving Babies' Lives Version Three*, pp 48–49
222 NHS England, *Saving Babies' Lives Version Three*, pp 48–49
223 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
224 QQ 54, 57–58 (Ciara Curran); Written evidence from Parent Advisory Group for East of England Neonatal Operational Delivery Network (PRT0050)
225 Written evidence from Abigail Mason-Woods (PRT0026)

underlying preterm labour, identify those women at greatest risk, and determine which interventions would most effectively support prevention.

Public health

101. Professor Lucy Chappell, Chief Executive Officer at NIHR and Chief Scientific Adviser at DHSC, told us that prevention of preterm birth "starts long before" a woman is pregnant.[226] This point was raised consistently by witnesses.[227] However, we heard that, based on analysis of the Royal College of General Practitioners dataset, "nine out of 10 women of reproductive age … are not in particularly good health."[228]

102. Kate Brintworth, Chief Midwifery Officer at NHS England, described this as the "context" for the limited improvements in preterm birth rates in recent years. She explained:

> "We are looking at a population who come to us in poorer health. Women tend to be older when they have their babies. They tend to weigh more. They have more hypertension, diabetes and a range of co-morbidities."[229]

Professor Marian Knight MBE, Professor of Maternal and Child Population Health and Director of the National Perinatal Epidemiology Unit, concluded: "We are not going to prevent preterm births solely by actions focused on maternity services."[230]

103. RCOG told us:

> "Supporting good health across the population, women's health across their life course, and good health in an individual's preconception period, are all dependent on and relevant to, reducing the overall incidence of preterm birth."

It urged the Committee to "consider the role of population level interventions to improve health and tackle inequalities more widely".[231] The Association of Directors of Public Health agreed that:

> "Population-level measures to improve the nation's health as a whole are most effective at reducing the rates of preterm births".[232]

104. Professor Judith Stephenson, Professorial Researcher and Honorary Consultant in Public Health/Sexual and Reproductive Health at University College London, also suggested that addressing risk factors for preterm birth "together as a group" via public health interventions would have a greater impact than "picking one or two" to target. In her view, given the wide range of risk factors associated with preterm birth, "there is no magic bullet here".[233]

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226 Q 256 (Prof Lucy Chappell)
227 Q 66 (Prof Anna David) and QQ 167, 170 (Prof Judith Stephenson); Written evidence from ESMI II Research Team (PRT0071) and Royal College of Obstetricians and Gynaecologists (PRT0072)
228 Q 167 (Prof Judith Stephenson)
229 Q 245 (Kate Brintworth)
230 Q 5 (Prof Marian Knight MBE)
231 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
232 Written evidence from Association of Directors of Public Health (PRT0086)
233 Q 167 (Prof Judith Stephenson)

105. As part of this, both RCOG and Prof Stephenson emphasised the importance of access to information on preconception health and pregnancy planning.[234] This was echoed by Prof Knight. She suggested, however, that this "falls between different parts of the healthcare system" at present: "It is not clear where women should go to get that advice."[235] She called for a "a clear place" where this kind of support could be accessed, as well as a clear source of funding.[236]

106. Professor Anna David, Professor in Obstetrics and Maternal Fetal Medicine at University College London, argued that there is underinvestment in this area of the healthcare system.[237] Raising similar points, other witnesses drew attention to cuts to the public health grant in recent years.[238] Figures highlighted by RCOG suggested that there has been, since 2015–16,

> "a 39% reduction for sexual health services, 34% reduction for public health advice, 31% reduction for drug and alcohol services for young people, and 12% in stop smoking services."[239]

107. The 2024 Labour manifesto stated that "Labour will prioritise women's health as we reform the NHS."[240] Baroness Merron, Parliamentary Under-Secretary of State for Patient Safety, Women's Health and Mental Health, assured the Committee that, as part of the new Government's overall emphasis on prevention, ensuring "that the health of women is optimised before we get to pregnancy" would be an important area of focus for her team. Echoing comments made by other witnesses,[241] she suggested that healthcare professionals should initiate conversations about pregnancy planning during existing points of contact, such as when a woman accesses contraception services.[242]

108. **Optimising women's health prior to pregnancy is an important element of preterm birth prevention. This includes addressing social deprivation and potential risk factors such as smoking, drug use, obesity and mental health problems. An increased focus on this is likely to be necessary to achieve the kind of reduction in the preterm birth rate envisaged by the maternity safety ambition. We welcome, therefore, the emphasis the new Government has placed on prevention and prioritising women's general health.**

109. ***The Government should set out how, as part of its strategy for women's health, it will ensure that all women have access to information and advice on pregnancy planning and preconception health at an appropriate time.***

234 Q 167 (Prof Judith Stephenson); Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
235 Q 6 (Prof Marian Knight MBE)
236 Q 15 (Prof Marian Knight MBE)
237 Q 66 (Prof Anna David)
238 Q 170 (Prof Judith Stephenson); Written evidence from Institute of Health Visiting (PRT0083) and Association of Directors of Public Health (PRT0086)
239 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
240 Labour Party, *Labour Party Manifesto 2024*, p 103
241 Q 170 (Prof Andrew Shennan OBE, Prof Judith Stephenson)
242 Q 257 (Baroness Merron)

CHAPTER 4: OPTIMISING OBSTETRIC AND NEONATAL CARE

Implementing national guidance

110. Although witnesses identified some limitations with the approach to preterm birth prevention set out in national clinical guidance for preterm birth,[243] there was consensus that, overall, the recommended interventions improve outcomes for preterm babies.[244] On the perinatal optimisation interventions,[245] we heard specifically that delayed cord clamping[246] can "reduce mortality by up to half" for preterm babies.[247] Ensuring that extremely preterm babies are born in a hospital with a level 3 neonatal unit was also highlighted as "an absolutely critical intervention" that significantly improves survival rates.[248]

111. The Department of Health and Social Care (DHSC) explained that maternity providers were required to implement version 3 of the SBLCB fully by March 2024. It argued that there had been "good progress against this target, driven by the maternity incentive scheme (MIS)."[249] Professor Donald Peebles, National Clinical Director for Maternity, NHS England, also suggested there was "evidence of real improvement." He told us:

> "The most recent compliance data with all elements of the care bundle was 87%. It has improved quite significantly over the last two or three years."[250]

112. The latest provider performance results, published in April 2024, show that 104 of the 120 participating trusts met the requirements of the SBLCB element of the MIS. This is an increase from 82 the previous year.[251] However, the latest MIS guidance outlines that,

> "where full implementation is not in place, compliance can still be achieved if the [integrated care board] confirms it is assured that all best endeavours—and sufficient progress—have been made towards full implementation".[252]

113. Prof Peebles told us that these allowances were made because "we introduced those interventions as a block in 2023", and requiring them to be fully implemented within a year "seemed to be unreasonable". He suggested this

243 See paras 84–85 and 93–95.
244 QQ 69–71 (Prof Chris Gale, Prof David Edwards, Dr Sarah Bates) and Q 136 (Dr Jenny Carter); Written evidence from British Association of Perinatal Medicine (PRT0042)
245 See footnote 221.
246 See glossary.
247 Q 67 (Prof Sarah Stock)
248 Q 34 (Prof Catherine Aiken)
249 Written evidence from Department of Health and Social Care (PRT0081) Established in 2018, the maternity incentive scheme aims to encourage NHS trusts to "actively adopt best practices and implement essential safety measures". The programme rewards financially trusts that can demonstrate implementation of agreed 'safety actions'. In 2024, trusts must demonstrate that they have either fully implemented or are "on track to achieve compliance with" all six elements of the SBLCB, including element 5 on preterm birth. NHS Resolution, 'Maternity Incentive Scheme': https://resolution.nhs.uk/services/claims-management/clinical-schemes/clinical-negligence-scheme-for-trusts/maternity-incentive-scheme/ [accessed 20 June 2024]; NHS Resolution, *Maternity (and perinatal) Incentive Scheme Year Six* (April 2024) p 18: https://resolution.nhs.uk/wp-content/uploads/2024/04/MIS-Year-6-guidance.pdf [accessed 20 June 2024]
250 Q 246 (Prof Donald Peebles)
251 Data available at: NHS Resolution, 'Maternity Incentive Scheme' (June 2024): https://resolution.nhs.uk/services/claims-management/clinical-schemes/clinical-negligence-scheme-for-trusts/maternity-incentive-scheme/ [accessed 9 July 2024]
252 NHS Resolution, *Maternity (and perinatal) Incentive Scheme Year Six*, p 18

was a "way of setting a trajectory", adding: "Next year the levels that we expect people to achieve will be higher." He also noted that compliance data provided by NHS trusts are scrutinised by NHS Resolution, which runs the MIS.[253]

Inconsistent implementation

114. Notwithstanding the figures set out above, we heard repeatedly that implementation of the interventions recommended in national guidance has been inconsistent and, in some cases, under-resourced. Witnesses suggested that this results in variation in care and poorer outcomes for babies who are born preterm.[254] Some suggested that variation was a key factor in the lack of progress to reduce the preterm birth rate in England to 6%.[255]

115. Prof Peebles acknowledged that, under the headline figure of 87% compliance, implementation of the perinatal optimisation interventions set out in the SBLCB is "more mixed".[256] Professor Sam Oddie, National Clinical Lead at the National Neonatal Audit Programme (NNAP), provided examples. He told us that delayed cord clamping is delivered to between "eight out of 10 and below three out of 10 babies" across neonatal units, while the use of a non-invasive approach to ventilation varied between 20% and 70%. He suggested that "there are strikingly different clinical styles of treatment for babies."[257]

116. NNAP's latest report, based on 2023 data, outlined that 52.9% of mothers received antenatal steroids in the week prior to delivery,[258] and 62% of preterm babies received their mother's milk in the first two days of life.[259] Dr Sarah Bates, Consultant Paediatrician and Neonatologist at Great Western Hospitals NHS Trust, set out that just 15% of preterm babies in England and Wales are getting all of the core perinatal interventions, ranging between 10% and 25% across different regions.[260]

Reducing variation in care

Regional care bundles

117. Dr Catherine Aiken, Associate Professor and Honorary Consultant in Fetal and Maternal Medicine at Cambridge University Hospitals, told us that there can be "a dichotomy" between standardised national guidance and local pathways. Regional implementation toolkits or care bundles are a potential means of addressing this. She told us that the PERIPrem care bundle, for example, "is a good bridge between what exists nationally as top-level guidance and implementation of services into what is present in a local

253 Q 250 (Prof Donald Peebles)
254 Q 21 (Clea Harmer), Q 40 (Prof Asma Khalil) and Q 71 (Dr Sarah Bates); Written evidence from Sands and Tommy's Joint Policy Unit (PRT0045), Bliss (PRT0063) and Royal College of Obstetricians and Gynaecologists (PRT0072)
255 Q 21 (Clea Harmer, Kath Abrahams, David Badcock)
256 Q 246 (Prof Donald Peebles)
257 Q 77 (Prof Sam Oddie)
258 Royal College of Paediatrics and Child Health, *National Neonatal Audit Programme (NNAP) Summary report on 2023 data* (October 2024): https://www.rcpch.ac.uk/sites/default/files/2024-10/nnap_summary_report_on_2023_data_0.pdf [accessed 22 October 2024]. This ranged from 40.7%–61.1% across neonatal networks and refers to mothers of babies born at less than 34 weeks in Great Britain.
259 Royal College of Paediatrics and Child Health, *Summary report on 2023 data*. This ranged from 41.4%–78.3% across neonatal networks and refers to babies born at less than 34 weeks in Great Britain.
260 Q 71 (Dr Sarah Bates)

network."[261] Professor Jonathan Benger, Chief Medical Officer and Interim Director of the Centre for Guidelines at NICE, agreed that care bundles are generally a useful tool to support the embedding of best practice.[262]

Box 4: PERIPrem

PERIPrem (Perinatal Excellence to Reduce Injury in Premature Birth) is a care bundle that includes 11 interventions. These include many of the perinatal optimisation interventions recommended in the SBLCB, as well as the use of probiotics and prophylactic hydrocortisone.[263] PERIPrem was developed by Health Innovation West of England, Health Innovation South West and the South West Neonatal Network. It was launched in April 2020 in those areas.

PERIPrem was developed from the quality improvement theory of a previous project focussed on preventing cerebral palsy (PReCePT). It also seeks to establish "new ways of working, where clinicians from obstetrics, midwifery and neonatal join together to drive forward and revolutionise care for preterm babies."[264]

118. Both Dr Bates and Prof Peebles suggested that PERIPrem had played an important role in quality improvement and facilitating the implementation of national guidance in the south-west of England.[265] Health Innovation West of England (HIWE) told us that it resulted in a 30% reduction in mortality of preterm infants and a 17% reduction in severe brain injury.[266] According to the National Child Mortality Database (NCMD), the south-west region had the lowest neonatal mortality rate in England in 2023.[267] HIWE suggested that the bundle has improved consistency of care, with the South West Neonatal Network now having the highest rate of delayed cord clamping and early breastmilk feeding.[268]

119. Dr Bates noted the "small financial investment" that was required to deliver the programme. Having a lead team in every unit, "with responsibility for focusing on and implementing the interventions", and using "real-time data to drive the improvement process constantly" were also key to its success, she felt.[269]

120. We heard that at least three other regions in England have now adopted PERIPrem.[270] Dr Lucinda Perkins explained that a version of it has also been introduced in Wales, resulting in "significant progress in reducing variation in perinatal optimisation".[271]

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261 Q 45 (Dr Catherine Aiken)
262 Q 243 (Prof Jonathan Benger CBE). Prof Benger noted, however, that NICE does not generally recommend care bundles, as grouping interventions together makes it more difficult to assess their individual effectiveness.
263 Health Innovation West of England, 'PERIPrem': https://www.healthinnowest.net/our-work/transforming-services-and-systems/periprem/ [accessed 9 July 2024]
264 Written evidence from Health Innovation West of England (PRT0011)
265 Q 71 (Dr Sarah Bates), QQ 246, 250 (Prof Donald Peebles)
266 Written evidence from Health Innovation West of England (PRT0011)
267 Written evidence from National Child Mortality Database (PRT0060)
268 Written evidence from Health Innovation West of England (PRT0011)
269 Q 71 (Dr Sarah Bates)
270 Written evidence from National Child Mortality Database (PRT0060) and Suffolk and Northeast Essex Local Maternity and Neonatal System (PRT0080)
271 Written evidence from Dr Lucinda Perkins (PRT0073)

Networks

121. Dr Aiken highlighted the opportunity to "reduce variation through a more networked approach", referring to the role of the neonatal operational networks (ODNs) and maternal medicine networks (MMNs).[272] Kelly Harvey, Senior Lead Nurse at the North West Neonatal Operational Delivery Network, explained how neonatal networks support providers to implement new national guidance by making it regionally operational. They can also provide training to make it "easier for an individual clinician in a service to understand the national guidance."[273] Both witnesses noted that the MMNs are currently far less developed than the ODNs, and that they would need to be strengthened in order to drive quality improvement.[274]

122. Professor Alexander Heazell, Professor of Obstetrics at the University of Manchester, highlighted that the preterm birth clinics in Greater Manchester have formed a network "which has enabled them to undertake region-wide quality improvements initiatives" and reduce variation between individual providers.[275] These clinical networks are promoted by the SBLCB to encourage shared learning and quality improvement.[276]

Training and staffing

123. RCOG argued that adequate staffing levels and "protected training time" were important factors in enabling services to implement the SBLCB guidance.[277] These points were raised consistently.[278] We heard, however, that this is a "challenge", because "everybody is stretched".[279] Dr Sundeep Harigopal, Clinical Lead at the Northern Neonatal Network, told us that whether staff are able to take up training "varies between hospitals depending on their staffing levels and their matrons' ability to release time … Even if it is done with webinars, nurses do not necessarily have the time allocated for them".[280]

124. This was echoed by Róisín McKeon-Carter, Chair of the Neonatal Nurses Association (NNA). She highlighted, for example, that nurses and midwives face barriers to completing training on neonatal resuscitation due to a lack of allocated training time and financial support, or there being insufficient staffing levels to backfill their shifts.[281][282] Resuscitation Council UK similarly reported that nurses and midwives in particular "struggle to access the study time and funding to access essential neonatal resuscitation training."[283]

Consolidating and updating guidance

125. Professor David Edwards, Professor of Paediatrics and Neonatal Medicine at King's College London, suggested that, for neonatal care, "there are

272 Q 39 (Dr Catherine Aiken). See Table 2 and para 6.
273 Q 158 (Kelly Harvey)
274 Q 39 (Dr Catherine Aiken) and Q 155 (Kelly Harvey)
275 Q 140 (Prof Alex Heazell)
276 NHS England, *Saving Babies' Lives Version Three*
277 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072). Staffing shortages are discussed in Chapter 4.
278 Q 40 (Prof Asma Khalil) and Q 158 (Kelly Harvey, Dr Sundeep Harigopal); Written evidence from Neonatal Nurses Association (PRT0074)
279 Q 158 (Kelly Harvey)
280 Q 158 (Dr Sundeep Harigopal)
281 Q 185 (Róisín McKeon-Carter)
282 Written evidence from Neonatal Nurses Association (PRT0074)
283 Written evidence from Resuscitation Council UK (PRT0076)

something like 18 national documents that it is obligatory for units to follow", along with around 30 other guidelines produced by organisations such as BAPM.[284] Professor Basky Thilaganathan, representing the Royal College of Obstetricians and Gynaecologists, told us:

> "Any given midwife or doctor has to remember somewhere around 1,500 recommendations and be able to deliver it in a context specific manner at any time of the day."

He argued that new technology, in particular the Tommy's app, could support clinicians by highlighting the relevant guidelines to follow in different circumstances. [285]

126. Prof Heazell suggested that some providers adapt national guidance to their own setting and may "water it down".[286] Caroline Lacy, LMNS Clinical Programme Lead at the NHS Somerset Integrated Care Board, agreed. She commented that providers also make guidance "more complex and harder to deliver." She suggested that national guidance should be translated on a regional basis, since "time spent on rewriting national guidance into local policy is terribly wasted."[287] Dr Catherine McParlin et al. highlighted that the North East, North Cumbria LMNS, in collaboration with their preterm birth clinical leadership group, developed a regional guideline, which was implemented across all their maternity units in 2021, and have sought to "standardise care provision".[288]

127. The British Maternal and Fetal Medicine Society recommended supporting "care providers with a single guideline".[289] Dr Aiken suggested that consolidating guidance could help to reduce variation in care, as guidance is generally updated at different times and is sometimes conflicting.[290] Dr Catherine McParlin et al. noted, for example, that there is currently "conflicting advice" between the RCOG guideline and the SBLCB on who to offer history-indicated cervical cerclage to.[291] Prof Benger explained that NICE are moving to a new modular approach to reviewing guidelines, to ensure they reflect the latest evidence.[292]

Data collection and monitoring

128. DHSC noted that data on preterm birth rates collected by the Office for National Statistics (ONS) is published annually, but with a lag of at least two years. This delay makes it more difficult to gauge the effectiveness of the interventions to reduce preterm birth introduced in the SBLCB:

> "We are currently working to reduce lags in the data on preterm birth rates; once we have ensured a timely data flow, we will be better able to evaluate how recent efforts have impacted outcomes."[293]

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284 Q 70 (Prof David Edwards)
285 Q 183 (Prof Basky Thilaganathan)
286 Q 139 (Prof Alex Heazell)
287 Q 222 (Caroline Lacy)
288 Written evidence from Dr Catherine McParlin, Dr Alex Patience and Dr Louise Michie (PRT0049)
289 Written evidence from British Maternal and Fetal Medicine Society (PRT0008)
290 Q 36 (Dr Catherine Aiken)
291 Written evidence from Dr Catherine McParlin, Dr Alex Patience and Dr Louise Michie (PRT0049)
292 Q 241 (Prof Jonathan Benger CBE)
293 Written evidence from Department of Health and Social Care (PRT0081)

NNAP data is also published annually, with a 10-month lag. More granular data is made available to individual neonatal units via an online dashboard.[294]

129. We heard from some witnesses that demonstrating compliance with the SBLCB through regular audits and data entry is very time-consuming for clinical staff due to the current IT systems, which also increase the likelihood of errors. They called for the introduction of a maternity dashboard that would display the data requested for SBLCB to support trusts and their LMNSs. They argued this would improve accuracy, and "ensure data is readily available … to help nationally benchmark and review outcomes."[295]

130. Challenges with data entry and linkage can also lead to data gaps, according to Dr Harigopal. He noted that while delayed cord clamping, for example,

> "is done by the midwife, the data is captured on the neonatal platform … Therefore, there is a gap in the first place, in that an intervention that may have been given is not necessarily captured."[296]

Professor Sam Oddie suggested that understanding "whether care delivery differs by ethnicity or deprivation" is similarly limited by a lack of available data. He noted: "Maternal ethnicity is quite commonly incomplete in routine datasets, which is very disappointing."[297]

131. Dr Harigopal suggested that neonatal nurses can spend "about one-third of the time for each shift" transcribing data, due to the lack of integration between digital records and patient monitoring systems.[298] Dr Aiken and Prof Khalil explained that issues with data sharing also make it more difficult for clinicians to access records from primary care, other hospitals and, sometimes, even services within the same hospital. Dr Aiken, concluded: "there are not ways of data sharing as easily and simply as there should be for maximally effective care"[299]

132. **While there is evidence to suggest that implementing existing guidance consistently would improve outcomes for preterm babies, and potentially reduce the preterm birth rate, there is currently significant variation in care between hospitals and regions. Regional networks and bodies have an important role to play in improving the implementation of guidance. Toolkits such as PERIPrem provide useful models for successful implementation that could be adopted more widely.**

133. ***The Government and NHS England must take further action to ensure the consistent implementation of clinical guidance relating to preterm birth, particularly the perinatal optimisation interventions set out in the Saving Babies' Lives Care Bundle. Every region should have the resources to adopt the methodology of implementation programmes that have been shown to be effective, and continue to strengthen maternal medicine and neonatal networks.***

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294 The NNAP data referenced in this report is from the 2024 audit, based on data from 2023. Q 77 (Prof Sam Oddie); Written evidence from Department of Health and Social Care (PRT0081)
295 Written evidence from Dr Angharad Care, Dr Rachel McFarland and Gemma Morgan (PRT0068)
296 Q 42 (Dr Catherine Aiken)
297 Q 83 (Prof Sam Oddie)
298 Q 165 (Dr Sundeep Harigopal)
299 QQ 42, 44 (Dr Catherine Aiken), Q 44 (Prof Asma Khalil)

Staffing

Multidisciplinary teams

134. Several witnesses emphasised the importance of a multidisciplinary team as part of optimising care for mothers at risk of preterm birth and their babies.[300] The SBLCB recommends that each trust should have a preterm birth lead team that includes an obstetric consultant, midwife, neonatal consultant and neonatal nurse.[301] Dr Carter particularly welcomed the inclusion of midwives in the team and highlighted their importance in preterm birth clinics.[302]

135. Prof Thilaganathan welcomed the introduction of specialist teams in principle, but questioned whether they would be successful in practice:

> "Just having people on paper as the preterm birth lead team does not mean the care will improve unless we liberate their time and afford them efforts to make an impact."[303]

The Committee did, however, hear examples of preterm birth lead teams working well. Leeds Teaching Hospitals NHS Trust noted that they have two specialist preterm midwives "working collaboratively" with the multidisciplinary lead team to "optimise care, experience and outcomes".[304]

136. Caroline Lee-Davey, Chief Executive of Bliss, highlighted that, along with neonatal nurses and doctors, allied health professionals (AHPs) are "critical" to neonatal care. AHPs include speech and language therapists, dietitians, occupational therapists and physiotherapists.[305] Prof Gale agreed.[306] Rachel Stamp et al, a group of neonatal network physiotherapy leads, argued that the availability of AHPs is necessary,

> "to fully optimise the development of the baby and the family unit, when establishing relationships and nurturing parenting behaviours is crucial for optimum long-term outcomes."[307]

137. Sharing further examples of the benefits of AHP involvement, the Neonatal Dietitians Group noted evidence showing that:

> "Early and focussed nutritional intervention lowers the risk and/or severity of co-morbidities of prematurity and adverse health outcomes, and improves cognition in later life."[308]

We heard too that support from speech and language therapists during neonatal care is "key to supporting longer-term outcomes in feeding/eating and drinking, speech, language, and communication".[309]

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300 Q 74 (Prof Chris Gale); Q 122 (Caroline Lacy) and Q 165 (Kelly Harvey); Written evidence from Royal College of Midwives (PRT0051) and Bliss (PRT0063)
301 NHS England, *Saving Babies' Lives Version Three*
302 Q 136 (Dr Jenny Carter)
303 Q 181 (Prof Basky Thilaganathan)
304 Written evidence from Leeds Teaching Hospitals NHS Trust (PRT0003)
305 Q 57 (Caroline Lee-Davey)
306 Q 73 (Prof Chris Gale)
307 Written evidence from Rachel Stamp, Joanne Adams, Charlotte Xanthadis, Emma Foulerton, Helen Cater, Maria Furtado, Anna Lukens, Denise Hart, Helen Robinson and Phillipa Ranson (PRT0036)
308 Written evidence from Neonatal Dietitians Group (PRT0020)
309 Written evidence from Royal College of Speech and Language Therapy Clinical Excellence Network (PRT0047)

138. Neonatal Leads for Psychological Practice in England highlighted the role of clinical psychologists as part of neonatal care, including the support they can provide for staff and managers in the neonatal unit. They argued: "Well supported staff are more present (less likely to be off sick), more productive and more able to be compassionate. This directly impacts the quality of care that infants and their families receive."[310]

Staffing shortages

139. The Royal College of Obstetricians and Gynaecologists (RCOG) noted: "Both the prevention of preterm birth, and ensuring the best outcomes for babies born preterm, requires an adequately staffed and well-supported workforce."[311] A common theme throughout our evidence, however, was that there are currently significant staff shortages across maternity and neonatal services. We also heard from NHS England that there is a need to keep staffing commitments "under constant review" given the increased complexity in the population[312] and the evolving expectations of care. Prof Peebles suggested that "the status quo", as well as current workforce targets, "will not be sufficient, going forward."[313]

Midwifery

140. The Royal College of Midwives (RCM) estimated that there is currently a shortage of 2,500 midwives in the NHS in England, according to the Birthrate Plus safe staffing formula.[314] NHS England committed in 2023 to meet establishment levels set by midwifery staffing tools and achieve fill rates by 2027–28.[315] Kate Brintworth, Chief Midwifery Officer at NHS England, said that recent investment in staffing "has paid off. We have more midwives in post now than we have ever had before." She suggested, however, that there is still a gap of around 1,900 staff.[316]

141. RCM acknowledged that the number of midwives is "now slowly rising". It welcomed the significant increase in the number of midwifery students across the UK over the last decade, and described the recently introduced midwifery apprenticeships as "a real success". It supported government plans for "5% of new midwives to enter the profession in England through apprenticeships by 2028."[317] Ms Brintworth agreed that, alongside the undergraduate pathway, this is "a really important route" into the workforce.[318]

142. However, a recent RCM report emphasised that the midwifery staffing shortage over recent years "has had an inevitable impact on maternity safety". It also highlighted the need to improve the retention rate among

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310 Written evidence from Neonatal Leads for Psychological Practice in England (PRT0052)
311 Royal College of Obstetricians and Gynaecologists (PRT0072)
312 See paras 101–02.
313 Q 247 (Kate Brintworth, Prof Donald Peebles)
314 Written evidence from Royal College of Midwives (PRT0051). Birthrate Plus is enshrined in NICE guidance and has been used since 2001. It is based on the "accepted standard of 1 midwife to 1 woman", as well as numerous local factors, to determine a recommended ratio of clinical midwives to births for each trust. Royal College of Midwives, *Birthrate Plus: What it is and why you should be using it*: https://pre.rcm.org.uk/media/2367/birthrate-plus-what-it-is-and-why-you-should-be-using-it.pdf [accessed 22 October 2024]
315 NHS, *NHS Long-term workforce plan* (June 2023), p 44: https://www.england.nhs.uk/wp-content/uploads/2023/06/nhs-long-term-workforce-plan-v1.2.pdf [accessed 9 July 2024]
316 Q 247 (Kate Brintworth)
317 Written evidence from Royal College of Midwives (PRT0051)
318 Q 248 (Kate Brintworth)

midwives.[319] Several witnesses highlighted that shortages in staffing are also limiting attempts to implement midwife continuity of carer (MCoC).[320] In 2022, NHS England suspended its targets for MCoC, noting that this will remain the case until staffing levels are sufficient to enable maternity services to provide it.[321]

Box 5: Midwife continuity of carer

The 2016 national maternity review, *Better Births*, included a vision to implement a continuity of carer model.[322] NHS England described this as "a way of delivering maternity care so that women receive dedicated support from the same midwifery team throughout their pregnancy".[323]

The 2019 NHS Long Term Plan included an aim to ensure that by 2021 "most women" would receive MCoC.[324] It referenced evidence from a 2016 Cochrane review that found that MCoC was associated with a 24% reduction in preterm birth. The review suggested: "Policy makers who wish to achieve clinically important improvements in … preventing preterm birth should consider midwife-led continuity models of care".[325]

This review was revised in 2024 and concluded then that MCoC models "may have little or no impact on the likelihood of preterm birth". However, women who received MCoC "reported more positive experiences during pregnancy, labour, and postpartum."[326] Ms Brintworth agreed: "Every evaluation of continuity says that it improves women's and families' experience. That was also my own experience."[327]

The Association for Improvements in Maternity Services suggested that MCoC could help to reduce inequalities in preterm birth rates and outcomes across ethnic groups. It acknowledged, however, that "the evidence in this area is conflicting".[328]

143. According to Ms Brintworth, it is "difficult to say" when those targets might be achieved.[329] Both Ms Brintworth and Baroness Merron, Parliamentary Under-Secretary of State for Patient Safety, Women's Health and Mental Health, stated that, in the intervening period, MCoC is being targeted at women from ethnic minority backgrounds and the most deprived areas.

319 Royal College of Midwives, *How to fix the midwifery staffing crisis*, (February 2024): https://pre.rcm.org.uk/media/7303/rcm_-how-to-fix-guide_-28-feb-2024.pdf [accessed 26 September 2024]
320 Q 41 (Dr Catherine Aiken), QQ 136–137 (Dr Jenny Carter); Written evidence from Royal College of Midwives (PRT0051)
321 NHS England, *Midwifery Continuity of Carer Letter* (September 2022): https://www.england.nhs.uk/wp-content/uploads/2022/09/B2011-Midwifery-Continuity-of-Carer-letter-210922.pdf [accessed 15 July 2024]
322 National Maternity Review, *Better Births*
323 NHS England, 'Continuity of Carer': https://www.england.nhs.uk/mat-transformation/implementing-better-births/continuity-of-carer/ [accessed 20 June 2024]
324 NHS, *Long-term plan* (January 2019): https://www.longtermplan.nhs.uk/wp-content/uploads/2019/08/nhs-long-term-plan-version-1.2.pdf [accessed 9 July 2024]
325 Jane Sandall et al, 'Midwife-led continuity models versus other models of care for childbearing women', *Cochrane Database of Systematic Reviews*, Issue 4 (2016): https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD004667.pub5/full [accessed 17 September 2024]
326 Jane Sandall et al, 'Midwife-led continuity of care models versus other models of care for childbearing women', *Cochrane Database of Systematic Reviews*, Issue 4 (2024): https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD004667.pub6/full [accessed 17 September 2024]
327 Q 249 (Kate Brintworth)
328 Written evidence from Association for Improvements in Maternity Services (PRT0038)
329 Q 249 (Kate Brintworth)

However, Baroness Merron told the Committee that it "cannot be acceptable" that it is offered "only in some areas."[330]

Obstetrics

144. We heard from RCOG that, within obstetrics and gynaecology, "rota gaps persist in many units". Survey data suggests this is also "one of the specialties most at risk of burnout." [331] Ms Brintworth told us: "We have more obstetricians than before, but we know that we still have gaps."[332]

145. RCOG emphasised that "inadequate staff numbers directly impact patient care and safety". It noted too that there is currently no equivalent to the Birthrate Plus formula to determine safe levels of staffing for obstetricians.[333] The previous Government commissioned RCOG to develop a tool that would "calculate the number of obstetricians at all grades required locally and nationally to provide a safe, personalised maternity service".[334] RCOG provided a prototype tool to the department in 2023, along with a final report estimating the number of obstetric staff required in England. It noted that plans for the next phase of the project have not yet been set out by the Government, and urged DHSC to progress this work.[335]

Neonatal

146. Professor James Boardman, Professor of Neonatal Medicine at University of Edinburgh, added: "It is incontrovertibly true that there is a staffing shortage in the neonatal workforce."[336] The NNA reported that in 2022 71.1% of neonatal rotas were staffed to the recommended minimum levels on average, with figures ranging from 56.8% to 85.3% across the country. This was despite funding for nurse staffing being made available after the publication of the 2019 NHS Long Term Plan, which identified a "a gap in neonatal nursing posts of approximately 2,000 nurses". The NNA also highlighted that a Getting It Right First Time (GIRFT)[337] report on the neonatology workforce has yet to be made publicly available by NHS England, despite it being completed in 2022.[338] Ms McKeon-Carter told the Committee: "If you do not have enough nurses, the outcomes for premature babies are poor".[339]

147. Rachel Stamp et al noted a "moderate improvement" in AHP staffing levels following the Neonatal Critical Care Transformation Review and Ockenden report. They suggested that they are, however, "still well below" BAPM safe staffing recommendations, and that some neonatal units have minimal or

330 Q 260 (Baroness Merron)
331 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
332 Q 247 (Kate Brintworth)
333 Health and Social Care Committee, *The Safety of Maternity Services in England* (Fourth Report, Session 2021–22, HC 19), p 12
334 Department of Health and Social Care, 'The government's response to the Health and Social Care Committee report: safety of maternity services in England': https://www.gov.uk/government/publications/safety-of-maternity-services-in-england-government-response/the-governments-response-to-the-health-and-social-care-committee-report-safety-of-maternity-services-in-england [accessed 9 July 2024]
335 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
336 Q 105 (Prof James Boardman)
337 See footnote 53.
338 Written evidence from Neonatal Nurses Association (PRT0074)
339 Q 181 (Róisín McKeon-Carter)

no AHP provision.[340] Other witnesses raised similar concerns.[341] NNA told us: "Currently neonatal nurses fill that void in care, but they are not the experts."[342]

148. DHSC told us that "growing and retaining the NHS neonatal workforce is a key priority." It noted that, in response to recommendations from the Neonatal Critical Care Transformation Review, NHS England has provided annual recurrent funding since 2021 to support the recruitment of neonatal nurses and allied health professionals. It added:

> "In 2023–24 a further investment of £3 million … is being specifically targeted at increasing medical staffing in neonatal intensive care and local neonatal units, to meet the BAPM standards, and to make provision in medical staff time for core safety and clinical governance work."[343]

149. **Despite recent improvements to staffing levels in some areas, maternity and neonatal services continue to be affected by significant staff shortages. This constrains the delivery of optimal, safe care for preterm babies and their families.**

150. ***It is imperative that the Government and NHS England meet the commitments to develop the maternity and neonatal workforce set out in the NHS Long-term Workforce Plan.***

Family integrated care

151. Witnesses noted that, while preterm babies are being treated on a neonatal unit, it is vital for parents to be active participants in their care. This can be facilitated through a family integrated care (FIC) model.[344] According to Bliss, FIC "builds on the foundations of family centred care", which it defines as care that involves "the family as much as possible in the daily care and routine of their baby."[345] Families can be involved in their baby's care during a stay in a NICU by, for example, holding, washing or feeding them.[346]

Benefits of family integrated care

152. Bliss highlighted that "ensuring parents can be partners in their baby's care is proven to be best for babies' developmental outcomes." It outlined evidence showing that FIC leads to a range of benefits including: increased weight gain, improved breastfeeding, better motor development, reduced risks of mortality and morbidity, and fewer days required in neonatal care. Nadia Leake, a parent and the author of *Surviving Prematurity*, reiterated this. She added that FIC has also been shown to reduce the prevalence of infection whilst in hospital.[347]

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340 Written evidence from Rachel Stamp, Joanne Adams, Charlotte Xanthadis, Emma Foulerton, Helen Cater, Maria Furtado, Anna Lukens, Denise Hart, Helen Robinson and Phillipa Ranson (PRT0036)

341 QQ 56–57 (Catriona Ogilvy, Caroline Lee-Davey); Written evidence from Royal College of Speech and Language Therapy Clinical Excellence Network (PRT0047), Kent, Surrey and Sussex Neonatal Operational Delivery Network (PRT0061) and Neonatal Nurses Association (PRT0074)

342 Written evidence from Neonatal Nurses Association (PRT0074)

343 Written evidence from Department of Health and Social Care (PRT0081)

344 Q 52 (Catriona Ogilvy) and Q 207 (Francesca Segal, Nadia Leake); Written evidence from Bliss (PRT0063)

345 Bliss, 'Family-centred care': https://www.bliss.org.uk/parents/in-hospital/looking-after-your-baby-on-the-neonatal-unit/family-centred-care [accessed 10 July 2024]

346 Bliss, 'Being involved in your baby's care and procedures': https://www.bliss.org.uk/parents/in-hospital/being-involved-in-your-babys-care-and-procedures [accessed 9 July 2024]

347 Q 207 (Nadia Leake)

153. On benefits for parents, Bliss stated that FIC "enables and empowers parents to become confident, knowledgeable and independent primary caregivers."[348] It noted evidence showing that it reduces stress and anxiety scores.[349] Francesca Segal, a parent and the author of *Mother Ship*, similarly stressed that FIC "empowers parents" and is "essential to promote an active early involvement that improves outcomes for parents and children alike."[350] Catriona Ogilvy, a parent and Chair of The Smallest Things charity, emphasised the significance to parents of being able to do simple things, such as changing their baby's nappy:

> "Some of the best experiences were when you could be a mum to your baby on the unit. That might sound a bit silly …. but in neonatal care that is a really difficult thing to do."[351]

154. Parents with experience of neonatal care surveyed in a national study highlighted how distressing it is "to be separated from their baby during their infant's neonatal admission, as a result of medical interventions or living long distances from the hospital."[352] Ms Segal told us that, "as in almost all neonatal units in this country", she was not permitted to stay during her preterm babies' 56 days in intensive care. She told us: "It is impossible to emphasise how much leaving felt like a daily amputation".[353]

Barriers to delivery

155. Several witnesses noted that there has been improvement in recent years with units moving towards a FIC model.[354] DHSC highlighted that it has invested in introducing care co-ordinator in each of the 10 neonatal networks in England:

> "The role of the neonatal care co-ordinator supports neonatal units across the region it serves to develop and implement family-centred and integrated care initiatives and improves the parent and family experience."[355]

156. Yet we heard from one parent advisory group that opportunities for parents to be involved in their babies' care differed across units in a single region.[356] Ms Leake suggested that, although care co-ordinators are supporting units with training, many staff are running their FIC programmes "out of goodwill on their days off".[357]

157. Ms Leake also argued that there is no real accountability to ensure FIC is being delivered fully, and its implementation has relied on the work of Bliss.[358] Bliss has produced a Baby Charter that seeks to place families at the centre of their baby's care. It provides a framework for neonatal units to self-assess

348 Bliss, 'What is FICare?' https://www.bliss.org.uk/health-professionals/family-integrated-care/what-is-ficare [accessed 9 July 2024]
349 Written evidence from Bliss (PRT0063)
350 Q 207 (Francesca Segal)
351 Q 52 (Catriona Ogilvy)
352 Written evidence from Katherine Sabin and Dr Fiona Challacombe (PRT0058)
353 Q 207 (Francesca Segal)
354 Q 52 (Catriona Ogilvy) and Q 207 (Nadia Leake); Written evidence from Adult Preemie Advocacy Network (PRT0066)
355 Written evidence from Department of Health and Social Care (PRT0081)
356 Written evidence from Parent Advisory Group for the East of England Neonatal Operational Delivery Network (PRT0050)
357 Q 211 (Nadia Leake)
358 Q 207 (Nadia Leake)

the quality of the family-centred care they deliver against a set of seven core principles.[359] UNICEF's Baby Friendly Initiative accreditation scheme also includes elements focused on enabling parents "to take an active part" in their baby's care while on the neonatal unit.[360]

158. These standards have been incorporated into the updated NHS England Service Specification for Neonatal Critical Care, published in March 2024. It sets out that:

> "Each neonatal unit must be supported to seek and acquire accreditation under the Bliss Baby Charter and the UNICEF Baby Friendly Initiative in order to facilitate the development of family integrated care".

Many of the outcomes and outputs defined in the specification are monitored using NNAP audit measures. This does not apply to adoption of the Bliss and UNICEF schemes. However, the specification states that "a range of tools must be in place to measure parent experience … in a form which can be nationally and regionally benchmarked."[361]

Accommodation

159. Witnesses suggested that a lack of overnight accommodation in neonatal units is a key barrier to FIC, as it results in parents being repeatedly separated from their babies.[362] A 2022 survey of parents conducted by Bliss found that:

> "75% did not have access to overnight accommodation when their baby was critically ill and 87% said this stopped them from being involved in their baby's care at least sometimes."[363]

160. Bliss also highlighted that in 2020 the GIRFT report found that only 30% of neonatal units met the standard for provision of overnight parental accommodation.[364] Ms Leake similarly emphasised that accommodation facilities are not generally available. This is in contrast with paediatric intensive care units, where parents can usually stay.[365]

161. Bliss highlighted that this is despite the NHS undertaking in the 2019 NHS Long Term Plan to "invest in improved parental accommodation." This was also listed as an "ambition" in the 2023 NHS Three year delivery plan for neonatal services.[366] The updated neonatal service specification requires "sufficient accommodation on or close to the neonatal unit for all families …

359 Bliss, 'What is the Baby Charter?': https://www.bliss.org.uk/health-professionals/bliss-baby-charter/what-is-the-baby-charter [accessed 10 July 2024]
360 UNICEF, 'About the Baby Friendly Initiative': https://www.unicef.org.uk/babyfriendly/about/ [accessed 22 October 2024]
361 NHS England, *Neonatal critical care: service specification* (March 2024): https://www.england.nhs.uk/wp-content/uploads/2015/01/Neonatal-critical-care-service-specification-March-2024.pdf [accessed 10 July 2024]
362 Q 54 (Caroline Lee-Davey) and Q 207 (Nadia Leake); Written evidence from Anonymous (PRT0007) and Bliss (PRT0063)
363 Written evidence from Bliss (PRT0063)
364 *Ibid.*
365 Q 207 (Nadia Leake)
366 NHS, Long-Term Plan, p 49; NHS England, *Three year delivery plan for maternity and neonatal services* (March 2023): https://www.england.nhs.uk/wp-content/uploads/2023/03/B1915-three-year-delivery-plan-for-maternity-and-neonatal-services-march-2023.pdf [accessed 10 July 2024]

to support family-centred care".[367] However, Bliss asserted that investment for these facilities has not been forthcoming.[368]

162. Ms Brintworth told us:

> "Staff recognise that having parents there is not just beneficial to the baby's health but absolutely fundamental to that baby going home well, but at times they are constrained by capital and estates."

She drew attention to the "huge variation" in NHS buildings. She noted too that: "The footprint that is allocated to maternity and neonatal services is often very limited by the trust."[369] NHS England has recently conducted a survey of its maternity and neonatal estates, in part to audit the availability of parental accommodation. Baroness Merron suggested that this was "the first time that such a survey had been conducted", and that it would "inform spending review planning".[370]

Financial barriers

163. Prof Edwards noted that poverty and deprivation are also barriers to parents engaging with FIC. He warned against investing in FIC in a "thoughtless way", to avoid increasing disparities in outcomes between poorer and more affluent families. Prof Gale agreed and told the Committee that "we need to provide support for families so that they can really undertake it, particularly for the most deprived groups in society."[371] A parent advisory group highlighted:

> "Fathers and non-birthing parents often have to return to work whilst their baby is still in neonatal care. Even mothers and birthing parents who are self-employed face this dilemma. This has a detrimental impact on implementing family integrated care and parent to child bonding."[372]

164. Ms Lee-Davey called for more financial support for parents. She also highlighted an "excellent" scheme in Scotland, the Young Patients Family Fund, which provides financial support throughout a baby's neonatal stay.[373] Ms McKeon-Carter noted that in North Devon District Hospital they are able to provide free accommodation, food and parking, and a hardship allowance for families, but they "rely heavily on the charity sector and on volunteers" to deliver it.[374] Witnesses welcomed the Neonatal Care (Leave and Pay) Act 2023,[375] which will require employers to provide up to 12 weeks of extra leave and pay for employees with responsibility for babies receiving

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367 NHS England, *Neonatal critical care: service specification*
368 Written evidence from Bliss (PRT0063)
369 Q 252 (Kate Brintworth)
370 Q 264 (Baroness Merron)
371 Q 73 (Prof Chris Gale)
372 Written evidence from Parent Advisory Group for the East of England Neonatal Operational Delivery Network (PRT0050)
373 Q 56 (Caroline Lee-Davey)
374 Q 191 (Róisín McKeon-Carter)
375 The Neonatal Care (Leave and Pay) Act 2023 is expected to be implemented in April 2025. To be eligible, the baby must have received neonatal care for more than seven continuous days before the baby reaches 28 days of life. Bliss, 'Neonatal Leave and Pay Campaign': https://www.bliss.org.uk/research-campaigns/influencing-policy-and-working-in-parliament/neonatal-leave-and-pay-campaign [accessed 10 July 2024]; Neonatal Care (Leave and Pay) Act 2023

neonatal care once it is implemented.[376] Ms Ogilvy told the Committee, however, that "families need lots more support."[377]

165. **Supporting parents to be involved closely in their babies' care while on the neonatal unit is an essential part of improving outcomes for preterm babies and their families. However, barriers to the delivery of family integrated care continue to exist. The availability of parental accommodation is inadequate in most cases, despite the promise of investment set out in the NHS Long Term Plan.**

166. ***NHS England should publish the findings of its maternity and neonatal estates survey, setting out what proportion of neonatal units are currently able to provide sufficient accommodation for all families, as per the updated service specification for neonatal critical care.***

167. ***In addition, the Government and NHS England should set out their plans for future investment in parental accommodation on neonatal units, to support improved provision of family integrated care.***

376 Q 51 (Caroline Lee-Davey); Written evidence from Nadia Griffin (PRT0079)
377 Q 51 (Catriona Ogilvy)

CHAPTER 5: FOLLOW-UP CARE AND SUPPORT

Care and support needs following discharge from hospital

168. We heard that the experience of being discharged home from the neonatal unit can be a "difficult period"[378] for preterm babies and their families. Parents must adjust to the fact that "they no longer fall within the protective zone of the neonatal unit", even though some will have been discharged home "with a baby who remains medically vulnerable".[379] As Catriona Ogilvy, a parent, and Chair and Founder of the charity The Smallest Things, put it:

> "Your experience of sitting in neonatal care is pretty much sitting by an incubator or a cot, with your baby attached to monitors that will constantly blink and alarm. The next morning you are at home, you are not attached to anything and nobody is with you. That can be quite a frightening thing."[380]

169. Parents frequently have to manage ongoing medical difficulties or additional care needs, such as tube feeding, after their baby leaves neonatal care.[381] Readmissions to hospital are also common.[382] A 2022 survey of parents whose children had recently received treatment in a UK NICU found that 36% "did not feel that they were well supported with their infant's specialised care needs" following discharge home.[383]

170. The same study found that emotional and psychological support was reported as "the area of greatest unmet need" in this period, as parents manage the "enduring psychological impact" of their neonatal care stay.[384] Indeed, we heard that this impact is often experienced "only after discharge from hospital",[385] and that it can be "felt most acutely" at this time.[386] The Neonatal Leads for Psychological Practice in England group cited research suggesting that up to 40% of mothers experience symptoms of post-traumatic stress disorder six months after a preterm birth, with one in four mothers "experiencing these symptoms for up to 18 months".[387]

171. Witnesses told us that counselling support following a preterm birth is either "not in place"[388] or "not offered as standard."[389] We heard too that, although such conversations would be welcomed, women do not typically have an opportunity to discuss with health professionals why they delivered early.[390] Ciara Curran, Founder of Little Heartbeats, recommended that for women

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378 Written evidence from Networks Neonatal Outreach Group (PRT0022)
379 Written evidence from Dr Rachel Collum and Lady Sarra Hoy (PRT0031)
380 Q 52 (Catriona Ogilvy)
381 Written evidence from Parent Advisory Group for East of England Neonatal Operational Delivery Network (PRT0050) and Katherine Sabin and Dr Fiona Challacombe (PRT0058)
382 Written evidence from Dr Sarah Seaton, Prof Elaine Boyle, Prof Samantha Johnson and Prof Brad Manktelow (PRT0027), The Smallest Things (PRT0032) and Katherine Sabin and Dr Fiona Challacombe (PRT0058)
383 Written evidence from Katherine Sabin and Dr Fiona Challacombe (PRT0058)
384 *Ibid.*
385 Written evidence from Dr Rachel Collum and Lady Sarra Hoy (PRT0031)
386 Written evidence from The Smallest Things (PRT0032)
387 Written evidence from Neonatal Leads for Psychological Practice in England (PRT0052)
388 Q 61 (Catriona Ogilvy)
389 Q 61 (Caroline Lee-Davy)
390 QQ 57, 60 (Ciara Curran); Written evidence from Parent Advisory Group for East of England Neonatal Operational Delivery Network (PRT0050)

who have experienced preterm birth, "there should be a referral so they can speak to their own obstetrician to go through what has happened".[391]

172. RCOG agreed that "improving access to specialist postnatal follow-up" for these women "should be a priority for the UK Government and the NHS". This would enable women to "discuss the reasons they gave birth prematurely and any mental health impacts, and to make a plan for their next pregnancy if relevant, to reduce the chance of recurrence." RCOG also urged the Government to consider "what additional support is needed" to enable health services to provide postnatal psychological support for women who give birth preterm.[392]

173. NHS England told us that:

> "Women have a right to request a debrief to discuss the circumstances of their birth, and our expectation is that maternity services make women aware of the availability of this service and meet these requests as quickly as possible."[393]

Kate Brintworth, Chief Midwifery Officer at NHS England, noted that NHS England has been establishing perinatal mental health services in each integrated care system, "so that they have a defined offer for people who have experienced trauma." She added: "We need to make absolutely sure that that includes those who have had a preterm birth and recognition of how shocking it is."[394]

174. Several witnesses emphasised how expert early intervention in the period after discharge home can lead to improved outcomes for preterm babies and their families.[395] A 2024 Cochrane review reported similar findings.[396] In this context, the Committee heard about a targeted follow-up intervention for very preterm babies developed in the Netherlands, known as the TOP programme.

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391 Q 60 (Ciara Curran)
392 Written evidence from Royal College of Obstetricians and Gynaecologists (PRT0072)
393 Letter from Kate Brintworth, Prof Donald Peebles and Dr Ngozi Edi-Osagie, NHS England, to Lord Patel, Chair of Preterm Birth Committee, 26 September 2024: committees.parliament.uk/publications/45370/documents/224935/default/
394 Q 252 (Kate Brintworth)
395 Written evidence from Ei SMART CIO (PRT0024), Rachel Stamp, Joanne Adams, Charlotte Xanthadis, Emma Foulerton, Helen Cater, Maria Furtado, Anna Lukens, Denise Hart, Helen Robinson and Phillipa Ranson (PRT0036) and Royal College of Occupational Therapists (PRT0067)
396 Jane Orton et al, 'Early developmental intervention programmes provided post hospital discharge to prevent motor and cognitive impairment in preterm infants', *Cochrane Database of Systematic Reviews*, Issue 2 (2024): https://www.cochranelibrary.com/cdsr/doi/10.1002/14651858.CD005495.pub5/full [accessed 12 September 2024]

Box 6: The Netherlands TOP programme

This programme provides parents of babies born before 32 weeks' gestation[397] with information about their child's development, and the impact of preterm birth, to improve parental responsiveness during the first year after discharge from hospital.[398] The intervention includes home visits by a physical therapist and a personalised parental report. It is provided free of charge and now reaches 80% of the population following a 12-year implementation process, initiated in 2006.[399]

The programme was developed in light of evidence showing that very preterm babies are "less responsive and explorative, have more feeding and sleeping difficulties, and experience more stress and behavioural disorganisation." As a result "these families are at high risk for difficulties in parent-child interactions, resulting in an additional risk factor for poorer child outcomes."[400] Dr Martine Jeukens-Visser, who led a recent study into the programme, highlighted that it has resulted in positive developmental improvements for preterm babies, as well as a reduction in hospital readmissions.[401] The programme has also achieved high levels of parental satisfaction.[402]

175. Witnesses also described how specialist neonatal outreach care can facilitate the transition home by, for example, reducing the length of hospital stays, minimising avoidable readmissions and providing support for parents.[403] The Networks Neonatal Outreach Group (NNOG) recommended that "all families should have access to a multi-disciplinary neonatal outreach service"; enabling them to be cared for at home would "improve physiological and psychological health outcomes … and support cot capacity across neonatal and maternity departments nationally." BAPM's service and quality standards for neonatal care similarly call for all units to develop outreach services, and proposed that outreach support should be available seven days a week.[404] According to NNOG, however, there is currently "huge inequity of access" to these services. It estimated that 31% of neonatal units in England instead "discharge families straight to generic health visiting care or paediatric community nursing teams".[405]

Health visiting services

176. All new babies are offered regular reviews with a health visitor. These typically take place within 10 to 14 days, at six to eight weeks, at one year,

397 Or if their birth weight is below 1,500 grams.
398 Q 203 (Dr Martine Jeukens-Visser)
399 Q 203 (Dr Martine Jeukens-Visser); Nienke M. Halbmeijer et al, 'Development and nationwide implementation of a post-discharge responsive parenting intervention program for very preterm born children: The TOP program' *Infant Mental Health Journal (2021):* https://www.sciencedirect.com/science/article/pii/S0022347623001361 [accessed 7 November 2024]
400 Nienke M. Halbmeijer et al, *Development and nationwide implementation of a post-discharge responsive parenting intervention program for very preterm born children: The TOP program*
401 Q 203 (Dr Martine Jeukens-Visser)
402 Nienke M. Halbmeijer et al, *Development and nationwide implementation of a post-discharge responsive parenting intervention program for very preterm born children: The TOP program*
403 QQ 183, 186 (Róisín McKeon-Carter); Written evidence from Networks Neonatal Outreach Group (PRT0022), Parent Advisory Group for East of England Neonatal Operational Delivery Network (PRT0050) and Department of Health and Social Care (PRT0081)
404 British Association of Perinatal Medicine, *Service and Quality Standards for Provision of Neonatal Care in the UK* (November 2022) p 9, 22: https://hubble-live-assets.s3.eu-west-1.amazonaws.com/bapm/file_asset/file/1494/BAPM_Service_Quality_Standards_FINAL.pdf [accessed 7 November 2024]
405 Written evidence from Networks Neonatal Outreach Group (PRT0022)

and at two to two and a half years after birth.[406] The Institute of Health Visiting (IHV) described health visitors as "the only service which proactively and systematically reaches all families with babies and young children". It highlighted their "key role" in ensuring that preterm babies and their parents receive appropriate, co-ordinated care in the community.[407]

177. IHV told us:

> "Whilst some babies will have their additional needs recognised during their stay in the neonatal unit, many health and developmental impacts will only be identified through robust follow-up and monitoring of progress over time".[408]

Witnesses reminded us that the health and wellbeing needs of parents, too, may not be apparent until weeks or months after discharge home.[409]

178. The Smallest Things agreed that health visitors are "uniquely placed to support families and children born prematurely in a journey we know lasts long after coming home from the hospital."[410] Nadia Leake, a parent and the author of *Surviving Prematurity*, described health visitors as "the only constant for many babies who have gone through a neonatal unit". She highlighted too their potential to provide interventions for preterm infants "that can support them to optimise their school attainment and life down the line".[411]

179. In his recent independent review of the NHS, Lord Darzi of Denham set out that health visitors "can be crucial to development in the first five years of life". He also identified "a worrying reduction" in their numbers, which "dropped by nearly 20% between 2019 and 2023".[412]

180. IHV told us this service had "been steadily eroded over the last nine years" and called for a reinstatement of the public health grant that funds it. The Association of Directors of Public Health said that "improving follow-up care cannot be done without an increase in public health funding".[413] Baroness Merron, Parliamentary Under-Secretary of State for Patient Safety, Women's Health and Mental Health, reiterated to the Committee the Government's commitment to train more health visitors, saying "that will be part of the workforce plan".[414]

The need for tailored health visitor support

181. The Networks Neonatal Outreach Group stated that, in addition to insufficient staffing levels, community nursing and health visiting teams "do not have the skill set … to meet the baby and families' needs at hospital

406 NHS, 'Your baby's health and development reviews' (November 2023) https://www.nhs.uk/conditions/baby/babys-development/height-weight-and-reviews/baby-reviews/ [accessed 3 September 2024]
407 Written evidence from Institute of Health Visiting (PRT0083)
408 Written evidence from Institute of Health Visiting (PRT0083)
409 Written evidence from Spoons (PRT0021), Abigail Mason-Woods (PRT0026), The Smallest Things (PRT0032) and Parent Advisory Group for East of England Neonatal Operational Delivery Network (PRT0050)
410 Written evidence from The Smallest Things (PRT0032)
411 Q 209 (Nadia Leake)
412 Prof Lord Darzi of Denham, *Independent Investigation of the National Health Service in England*, pp 38–40
413 Written evidence from Association of Directors of Public Health (PRT0086)
414 QQ 259, 264 (Baroness Merron)

discharge".[415] According to the Smallest Things, just 29% of parents of preterm babies it surveyed agreed that their health visitor understood their or their baby's needs.[416]

182. The charity Spoons similarly stated that:

> "Parents often tell us that their health visitor does not always understand the neonatal experience and the impact that this has on their mental health, or their babies' development and milestones."[417]

It identified "inconsistent information" as another "common frustration": "[parents] are told one thing by their baby's neonatal care team and something completely different by their health visitor".[418]

183. Dr Rachel Collum and Lady Sarra Hoy spoke of a "role-reversal", suggesting that "often it comes down to parents" to educate health visitors and GPs about the impact of prematurity. They highlighted the "unwarranted pressure" this can place on parents: "It should not be for mothers to educate or challenge health professionals who are trying to rely on incorrect information."[419] Spoons also emphasised the impact such issues can have on "parents who are already exhausted, overwhelmed, stressed and traumatised by a neonatal care stay".[420]

184. IHV told us that communication between maternity and community services "is not always adequate".[421] Witnesses with lived experience raised similar points about the lack of co-ordination between different healthcare settings.[422] IHV also acknowledged that "health visitor pre-registration training does not give sufficient attention to the specific needs of preterm babies and their families."[423] Caroline Lacy, LMNS Clinical Programme Lead at the NHS Somerset Integrated Care Board, made a similar point.[424] IHV suggested that this, alongside the fact that "continuous professional development opportunities for health visitors are determined locally", has "led to a gap in the workforce's ability to deliver high-quality consistent support to these families". It noted that health visitors themselves "did not feel equipped" to provide informed support.[425]

185. IHV said that a pilot training programme it delivered with the charity Tiny Lives Trust, aimed at improving health visitors' understanding of the needs of preterm babies and their parents, had been "evaluated positively". It suggested that the introduction of a similar, national programme warranted consideration.[426] Ms Leake welcomed the programme and agreed that it "must be wider reaching".[427]

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415 Written evidence from Networks Neonatal Outreach Group (PRT0022)
416 Written evidence from The Smallest Things (PRT0032)
417 Written evidence from Spoons (PRT0021)
418 *Ibid.*
419 Written evidence from Dr Rachel Collum and Lady Sarra Hoy (PRT0031)
420 Written evidence from Spoons (PRT0021)
421 Written evidence from Institute of Health Visiting (PRT0083)
422 Q 57 (Catriona Ogilvy); Written evidence from Abigail Mason-Woods (PRT0026) and Parent Advisory Group for East Of England Neonatal Operational Delivery Network (PRT0050)
423 Written evidence from Institute of Health Visiting (PRT0083)
424 Q 228 (Caroline Lacy)
425 Written evidence from Institute of Health Visiting (PRT0083)
426 *Ibid.*
427 Q 211 (Nadia Leake)

186. Ms Lacy told us that "the training and development of health visitors … is key".[428] She suggested that this could be delivered by the neonatal operational delivery networks, which "already have a fabulous network of training".[429] Dr Collum and Lady Hoy proposed that such training should form part of a programme to provide specialist health visitors for families who had been discharged from neonatal care.[430] Respondents to the 2022 study of parents mentioned above similarly called for support following discharge to be "provided by more experienced practitioners who have been specially trained".[431] The Smallest Things recommended that all health visiting teams and GP practices should have "a named and trained neonatal lead".[432]

187. **The period following discharge home from the neonatal unit can be a challenging time for preterm babies and their families. Many parents will require emotional, as well as practical, support as they begin to process the psychological impact of their time in neonatal care. Parents report that community healthcare professionals are often unable to provide the informed care and advice they need.**

188. **Specialist mental health and neonatal outreach services can play a key role in delivering such support. However, we heard that these are not always available. While health visitors do reach all families, they are poorly equipped to meet the specific needs of preterm babies and their parents due to their limited training on the impacts of prematurity.**

189. ***The Government and NHS England should detail the steps they are taking to ensure equitable access to neonatal outreach and perinatal mental health services for all families that experience preterm birth.***

190. ***NHS England should work with training providers to embed opportunities to develop specialist knowledge of the needs of preterm babies and their families into health visitor training and continuous professional development, with protected training time.***

Enhanced support and surveillance for babies born preterm

191. Guideline NG72 from the National Institute of Health and Care Excellence (NICE) sets out that, in addition to the health and development reviews that are offered to all babies, some preterm babies should receive enhanced developmental support and surveillance. The guidance states that this should be offered up until the age of two if a child who was born preterm:

    - has a developmental problem or disorder, such as motor function problems or a hearing impairment; or
    - is at increased risk of developmental problems or disorders because they were born
        - before 30 weeks' gestation, or
        - between 30 and 37 weeks' gestation and also have specific risk factors, such as brain injury.

428 Q 228 (Caroline Lacy)
429 Q 229 (Caroline Lacy)
430 Written evidence from Dr Rachel Collum and Lady Sarra Hoy (PRT0031)
431 Written evidence from Katherine Sabin and Dr Fiona Challacombe (PRT0058)
432 Written evidence from The Smallest Things (PRT0032)

The guidance outlines that babies who were born before 28 weeks should receive additional developmental support and surveillance up until the age of four.[433]

192. Enhanced developmental support is described by NICE as "additional advice and interventions with skilled professionals". These aim to "support [children born preterm and their parents] after discharge from hospital, respond to their concerns, and reduce the impact of any developmental problems and disorders." The purpose of enhanced surveillance is to monitor a child's development "at set times and using specific tools, to detect developmental problems and disorders".[434]

193. Professor Samantha Johnson, Professor of Child Development at the University of Leicester, set out that enhanced surveillance and support is offered "with a view to these problems being picked up early and the children being referred as early as possible for support".[435] Prof Johnson and Professor Neil Marlow, Emeritus Professor of Neonatal Medicine at University College London, argued that the developmental assessment at age four is "particularly important".[436]

194. In oral evidence, Prof Marlow went further:

> "There is a desperate need for the smallest babies to have some form of cognitive assessment before they go to school. The challenges of going to school when you have a low IQ, which is often unrecognised, mean that it can take two or three years for your issues to be identified, and those two or three years are critical to laying down patterns for development."

Assessment at age four had been recommended as it "offered the first follow-up point for doing real intervention".[437] Hilary Cruickshank, Clinical Specialist Neonatal Physiotherapist, NHS Lothian, and Chair, British Association for Neonatal Neurodevelopmental Follow-up (BANNFU), agreed that this assessment is "essential" and "something that we really need to push for".[438]

195. We heard, however, that access to neurodevelopmental follow-up "continues to be a postcode lottery, despite the publication of the NICE guideline".[439] Professor Sam Oddie, Consultant Neonatologist at Bradford Teaching Hospitals NHS Foundation Trust, and National Clinical Lead at the National Neonatal Audit Programme (NNAP), told us:

> "The proportion of babies who have any clinical information recorded at two years across the United Kingdom is not much in excess of 70%. There is enormous variation even between different parts of one city."[440]

433 NICE, 'Developmental follow-up of children and young people born preterm': https://www.nice.org.uk/guidance/ng72 [accessed 20 June 2024]
434 *Ibid.*
435 Q 124 (Prof Samantha Johnson)
436 Written evidence from Prof Samantha Johnson and Prof Neil Marlow (PRT0018)
437 Q 126 (Prof Neil Marlow)
438 Q 130 (Hilary Cruickshank)
439 Written evidence from Rachel Stamp, Joanne Adams, Charlotte Xanthadis, Emma Foulerton, Helen Cater, Maria Furtado, Anna Lukens, Denise Hart, Helen Robinson and Phillipa Ranson (PRT0036)
440 Q 84 (Prof Sam Oddie)

196. According to NNAP data, in 2023, 77% of very preterm children had a documented medical follow up at two years.[441] We heard from NHS England that this rate "continues to improve", having increased from 68.4% since 2020.[442] Yet figures for individual neonatal units varied from 61.7% to 90%.[443] In 2022, "only 24% (39 of 162) of units achieving the NNAP developmental standard of 90% of babies receiving a two year assessment".[444]

197. Ms Cruickshank reported data from a separate 2022 survey conducted by BANNFU, which found that 85% of UK neonatal units "were doing some form of neonatal follow-up until the age of two". In her view, "that is good, but we do not know about its quality".[445] Data on follow-up at four years is not collected by NNAP,[446] but the same BANNFU study reported that only 6.7% of neonatal units were conducting assessments at this stage.[447]

198. We heard from Prof Marlow that the responsibility for organising assessments at age four "has been placed very firmly by NICE with the neonatal unit".[448] By contrast, Baroness Merron stated that "the reason that only 6.7% of neonatal units are conducting the follow ups" is because "neonatal services do not have responsibility for providing them." The NICE guideline allocates this function to community paediatric services, she suggested.[449] NHS England made the same point, highlighting that these services are commissioned by integrated care boards. It also acknowledged that "the assessment is not routinely undertaken locally by community paediatric services", despite the guidance from NICE.[450]

199. Prof Johnson and Prof Marlow identified "a lack of clarity over who should be responsible for organising or carrying out the assessments" as one of several factors that may contribute to inconsistent provision. Other potential causes were limited resources and the absence of a routine system for recording and auditing assessment outcomes.[451] Professor Jonathan Benger, Chief Medical Officer and Interim Director of the Centre for Guidelines at NICE, said there had been "overwhelming feedback" that this "relates to resources". He added: "Commissioners balance priorities, and, sadly, that particular service does not appear to be widely delivered … in the NHS at the moment."[452]

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441 Available at Royal College of Paediatrics and Child Health, *Summary report on 2023 data*

442 Letter from Kate Brintworth, Prof Donald Peebles and Dr Ngozi Edi-Osagie, NHS England, to Lord Patel, Chair of Preterm Birth Committee, 26 September 2024: committees.parliament.uk/publications/45370/documents/224935/default/

443 Figures for units across England, Scotland and Wales. Available at Royal College of Paediatrics and Child Health, *Summary report on 2023 data*

444 Written evidence from Prof Samantha Johnson and Prof Neil Marlow (PRT0018)

445 Q 124 (Hilary Cruickshank)

446 National Neonatal Audit Programme, *A guide to the 2024 audit measures* (January 2024): https://www.rcpch.ac.uk/sites/default/files/2024-01/2024_nnap_audit_measures_guide_v1.0_0.pdf [accessed 3 September 2024]

447 Q 124 (Hilary Cruickshank)

448 Q 127 (Prof Neil Marlow)

449 Letter from Baroness Merron, Parliamentary Under-Secretary of State, Department of Health and Social Care, to Lord Patel, Chair of Preterm Birth Committee, 26 September 2024: committees.parliament.uk/publications/45369/documents/224930/default/

450 Letter from Kate Brintworth, Prof Donald Peebles and Dr Ngozi Edi-Osagie, NHS England, to Lord Patel, Chair of Preterm Birth Committee, 26 September 2024: committees.parliament.uk/publications/45370/documents/224935/default/

451 Written evidence from Prof Samantha Johnson and Prof Neil Marlow (PRT0018)

452 Q 243 (Prof Jonathan Benger CBE)

200. Ms Cruickshank suggested that to improve provision there is a need to "engage neonatal teams" and increase funding.[453] Witnesses proposed too that data on the completion rates and content of assessments at four years should be collected by NNAP, with results recorded in the National Neonatal Research Database and electronic patient records.[454]

201. **The Committee heard that follow-up assessments for children who were born preterm are essential in identifying additional support needs and opportunities for beneficial early intervention before children start school. Yet there is worrying evidence that these are not consistently delivered at ages two and four, despite being recommended in NICE guidance.**

202. **Provision of the assessment at age four appears to be especially low. We saw no evidence that action is being taken to address this failure, or to hold the relevant services accountable for delivery. Indeed, there even appears to be some uncertainty about where responsibility for these assessments lies.**

203. ***The Government and NHS England must take swift action to determine why the follow-up assessments recommended by NICE are not being consistently delivered, in particular at age four, and prioritise work to address this.***

The transition to school

204. Professor Dieter Wolke, Professor of Developmental Psychology and Individual Differences at the University of Warwick, suggested that the start of school can be another "highly stressful" time for children who were born preterm and their families: "Many parents are worried that their child is not mature enough to enter school according to the cut-off for school entry".[455] Ms Ogilvy echoed this point:

> "For parents who have had that experience of early trauma and ongoing and relived trauma, school can be quite a scary time. You worry about whether they are ready".[456]

In addition, Prof Johnson explained that "entering school is often a flashpoint" when the cognitive, social or emotional difficulties experienced by children who were born prematurely may emerge or become exacerbated.[457]

Accessing support in educational settings

205. As noted previously, children who were born preterm are more likely to have special educational needs and learning difficulties than those who are born at term.[458] The parents' charity Spoons suggested, therefore, that "premature birth should be a red flag for schools when identifying and supporting a child with difficulties".[459] We heard from one parents' group, however, that:

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453 Q 126 (Hilary Cruickshank)
454 Q 126 (Hilary Cruickshank); Written evidence from Prof Samantha Johnson and Prof Neil Marlow (PRT0018)
455 Written evidence from Prof Dieter Wolke (PRT0010)
456 Q 54 (Catriona Ogilvy)
457 QQ 129–30 (Prof Samantha Johnson)
458 See para 31.
459 Written evidence from Spoons (PRT0021)

> "Parents often report a lack of understanding and awareness of the longer-term implications of being born preterm and therefore a lack of support in educational settings".[460]

206. Ms Ogilvy noted that the educational needs of these children "can be quite subtle".[461] Prof Johnson added that the "special constellation of difficulties that preterm children have" means their needs may not be recognised easily by teachers: "If the parent does not mention prematurity, it can be overlooked". A potential solution, she suggested, would be for schools to ask about children's birth history on admission.[462]

207. The Smallest Things has facilitated this through its Prem Aware Award scheme.[463] This requires schools to update their registration forms, to encourage parents to provide information about their children's birth history. The charity told us that this enables teachers to identify those who were born preterm and "provide timely support". It argued that making this a statutory requirement "could be a simple yet crucial step in improving the long-term outcomes" of children born prematurely.[464] A similar programme is in place in Northern Ireland, delivered by the charity Tiny Life and supported by the Department for Education.[465]

208. Prof Johnson cautioned, however, that there is value in schools asking about children's birth history "only if the staff know what to do with that information". She underlined the need to train education professionals on the impacts of prematurity and how best to support children who were born prematurely, citing research from 2015 that found that only 13% of teachers had received any such training.[466] This call was echoed by Spoons and the Adult Preemie Advocacy Network.[467] To that end, the Prem Aware Award programme promotes the use of the PRISM resources for teachers developed by Prof Johnson and colleagues.[468]

Deferring or delaying school entry

209. The school admissions code for England states that parents are entitled to "seek a place for their child outside of their normal age group, for example if their child … has experienced problems such as ill health".[469] Parents can apply to defer school entry, so that their child starts school partway through the reception year or goes straight into year 1 in the September after they turn five.[470] Parents can also apply to delay school entry, so that their child's

460 Written evidence from Parent Advisory Group for East of England Neonatal Operational Delivery Network (PRT0050)
461 Q 54 (Catriona Ogilvy)
462 QQ 129–30 (Prof Samantha Johnson)
463 The Smallest Things, 'Prem Aware Award': https://www.thesmallestthings.org/prem-aware-award [accessed 11 September 2024]
464 Written evidence from The Smallest Things (PRT0032)
465 Tiny Life, 'Tiny Learners Award': https://www.tinylife.org.uk/support-for-schools/ [accessed 11 September 2024]
466 QQ 129–30 (Prof Samantha Johnson)
467 Written evidence from Spoons (PRT0021) and Adult Preemie Advocacy Network (PRT0066)
468 PRISM, 'Preterm Birth Information for Education Professionals': https://www.nottingham.ac.uk/helm/dev/prism/index.html [accessed 11 September 2024]
469 Department for Education, *School Admissions Code (September 2021)*, p 25: https://assets.publishing.service.gov.uk/media/60ebfeb08fa8f50c76838685/School_admissions_code_2021.pdf [accessed 11 September 2024]
470 Bliss, 'Options for starting primary school': https://www.bliss.org.uk/parents/growing-up/starting-primary-school/options-for-starting-primary-school [accessed 12 September 2024]

enters reception at age five.[471] Education is a devolved matter so requirements vary across the UK.[472]

210. Government guidance recognises that parents of children who were born prematurely may wish to delay their child's school entry. It states that, if the child would have fallen into the subsequent school year if they had been born at term, school admissions authorities should take this into account.[473]

211. Ms Leake highlighted the concerns parents may have:

> "If we think about the corrected age of a baby born four months early, when he is four years-old and supposed to be going into reception, cognitively, in his brain development, he is three years and eight months. He cannot catch up."

She argued that "there needs to be a huge amount of flexibility in education because of the risks for these children".[474]

212. Francesca Segal, parent and author of *Mother Ship*, suggested, however, that in her experience only some parents were "lucky enough to encounter comprehension" from teachers and local authorities when they sought to delay their child's school entry. Others faced "agonising school battles".[475] BANNFU told us:

> "Although it is possible to start reception at the age of five rather than four years, many admission authorities do not allow this in practice and schools may be reluctant to support applications".[476]

213. BANNFU commented too that "application to delay starting school can be complicated and varies from one admission authority to another".[477] Guidance from Bliss sets out the kinds of supporting evidence required for an application to delay starting school, which include letters from medical professionals involved in the child's care.[478]

214. Ms Leake and Ms Segal emphasised that not all parents will be equally equipped to navigate the complex application process.[479] BANNFU similarly noted that "a successful application … depends on the case put forward by parents and carers". Supporting evidence "will often be influenced by ethnic

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471 Department for Education, 'Summer born children starting school: advice for parents' (April 2023): https://www.gov.uk/government/publications/summer-born-children-school-admission/summer-born-children-starting-school-advice-for-parents [accessed 12 September 2024]

472 In Scotland, parents have a legal right to delay school entry if their child is not yet five at the time they are due to start school. A bill passed in Northern Ireland in 2022 allows parents of children who are 'young for year' to delay their school entry. This entitlement also applies to children who were born prematurely but would have been young for year if born at term. Scottish Government, 'Choosing a school for your child' (November 2022): https://www.mygov.scot/register-your-child-for-a-school; Northern Ireland Department of Education, 'School Starting Age': https://www.education-ni.gov.uk/topics/curriculum-and-learning/school-starting-age [accessed 16 September 2024]

473 Department for Education, 'Summer born children starting school: advice for parents' (April 2023): https://www.gov.uk/government/publications/summer-born-children-school-admission/summer-born-children-starting-school-advice-for-parents [accessed 12 September 2024]

474 Q 209 (Nadia Leake)

475 Q 209 (Francesca Segal)

476 Written evidence from British Association for Neonatal Neurodevelopmental Follow-Up (PRT0070)

477 *Ibid.*

478 Bliss, 'Checklist for applications to defer or delay': https://www.bliss.org.uk/parents/growing-up/starting-primary-school/deferring-or-delaying-application-checklist [accessed 11 September 2024]

479 Q 209 (Nadia Leake, Francesca Segal)

and socioeconomic factors which frequently underlie preterm birth, thus potentially contributing further to inequality".[480]

215. Ms Segal concluded that, "as a minimum, school deferral needs to be an automatic availability" for children in England born before a specified gestational age. This would "protect the parents who are not able to fight those bureaucratic battles"[481] BANNFU proposed that parents should be allowed to decide in which year their prematurely born child starts school if their expected due date and date of birth fall in different school years, "without having to collect evidence supporting their application".[482]

216. Prof Wolke felt that, for children who fall into this group, it would be a "sensible policy" to enable parents to delay school entry. He added, however:

> "Our evidence also shows that it is preferrable for all other preterm born children not to delay school entry but rather to train teachers to provide adequate support in school".[483]

Guidance from Bliss similarly suggests that "there is no firm evidence" on the benefits of delaying school entry for children who were born prematurely. Moreover, "school may actually be the best place for them to receive the specialist support they need from the earliest opportunity."[484]

217. **We support the ambition of programmes such as the Prem Aware Award scheme to increase awareness of the impacts of prematurity in schools. Enhancing understanding among education professionals has the potential to facilitate the transition to school for families, enable appropriate support to be provided during school and improve outcomes for children born prematurely.**

480 Written evidence from British Association for Neonatal Neurodevelopmental Follow-Up (PRT0070)
481 Q 207 (Francesca Segal)
482 Written evidence from British Association for Neonatal Neurodevelopmental Follow-Up (PRT0070)
483 Written evidence from Prof Dieter Wolke (PRT0010)
484 Bliss, 'Options for starting primary school': https://www.bliss.org.uk/parents/growing-up/starting-primary-school/options-for-starting-primary-school [accessed 12 September 2024]

CHAPTER 6: RESEARCH

Research priorities

218. As noted above, understanding of the molecular mechanisms that initiate preterm labour is currently limited.[485] Professor Sarah Stock, Professor of Maternal and Fetal Health at the University of Edinburgh, told us that, consequently, there is "an absolute need" for discovery research in this area.[486] This point was raised consistently by witnesses.[487]

219. Professor Mark Johnson, Clinical Chair in Obstetrics at Imperial College London, explained:

> "It is essential that we … find the mechanism, in order to have treatments that might stand a success of treating it."[488]

Prof Stock suggested that an improved understanding of "changes that happen around the time of parturition" would also assist with "monitoring and diagnosis, and making sure that we can time therapies that we know can be lifesaving".[489]

220. We heard from Professor David MacIntyre, Professor of Reproductive Systems Medicine at Imperial College London, that "good advancements are being made" in certain related areas. He noted, for example, recent analysis of the microbiome of the reproductive tract, suggesting that this is a promising area of research to improve understanding of preterm birth and develop treatment interventions.[490]

221. Dr Catherine Aiken, Associate Professor and Honorary Consultant in Fetal and Maternal Medicine at Cambridge University Hospitals, agreed that discovery research could assist with identifying "targetable areas" that clinicians could treat. She cautioned, however, that "starting at the bottom of the pathway, when the preterm birth is imminent or occurring, is very challenging". She emphasised the corresponding need for "research that is wide-ranging and longitudinal in its scope". This should examine "the entire paradigm of preterm birth, which begins pre-conception and ends with the long-term health of the child."[491]

222. Other witnesses made similar calls for research into the wider health and societal risk factors associated with preterm birth. It was suggested that this could, for example, enable us to "test theories about what drives inequalities" in preterm birth rates across different groups of women;[492] "identify and evaluate non-medical interventions that reduce preterm births";[493] and provide evidence on how such interventions could be targeted most effectively.[494]

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485 See paras 96–97.
486 Q 64 (Prof Sarah Stock)
487 Q 14 (Dr Jennifer Jardine), Q 48 (Dr Catherine Aiken), and QQ 64, 67 (Prof David MacIntyre); Written evidence from Prof Neena Modi (PRT0037)
488 Q 64 (Prof Mark Johnson)
489 Q 64 (Prof Sarah Stock)
490 Q 64 (Prof David Macintyre)
491 Q 48 (Dr Catherine Aiken)
492 Written evidence from Sands and Tommy's Joint Policy Unit (PRT0045)
493 Written evidence from Prof Neena Modi (PRT0037)
494 Q 14 (Prof Marian Knight MBE)

223. Professor James Boardman, Professor of Neonatal Medicine at University of Edinburgh, highlighted a need to "raise awareness in the research and clinical communities that preterm morbidities and mortalities start in the antenatal period." If we understand the factors that affect babies in utero and lead to outcomes such as preterm brain injury, "the potential window for targeting interventions broadens out significantly", he argued.[495] Overall, he felt there should be "renewed attention on neuroprotective and neurorestorative interventions for preterm infants", since neurodevelopmental problems are "the most prevalent" adverse outcome of preterm birth.[496]

224. Professor Chris Gale, Professor of Neonatal Medicine, Imperial College London, suggested that long-term cohort studies should be prioritised, to examine the effects of neonatal treatments "across all aspects of … learning, behaviour and development" in individuals who were born prematurely. These should continue into adulthood, in view of the "later life impacts" of preterm birth [497] Prof Boardman raised similar points, emphasising the value of the EPICure cohort studies that were conducted in the 1990s and early 2000s.[498] He also highlighted the importance of discovery research in relation to neonatal care, telling us: "At a very basic level, some of the pathophysiology of the diseases we are trying to treat is very poorly understood".[499]

225. Other research priorities identified by witnesses included studies focused on the effectiveness of clinical interventions, to determine their optimal targeting, timing and dosage; and implementation, to examine how best to ensure that research findings are embedded into practice.[500]

Barriers to research

Funding

226. According to a 2020 study into pregnancy research conducted by RAND, "for every £1 spent on pregnancy care in the NHS, less than 1p is spent on pregnancy research in the UK." It estimated that the total annual spend on pregnancy research between 2013 and 2017 was £51 million, "significantly less than spending on other conditions" such as heart disease and cancer.[501]

227. The Medical Research Council (MRC)[502] is the second largest funder of pregnancy research in the UK.[503] Analysis by *Nature* suggested that MRC provided £96 million of funding for research across all aspects of women's health between 2014 and 2019. This was "roughly equivalent to its spending

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495 Q 89 (Prof James Boardman)
496 Q 85 (Prof James Boardman)
497 Q 74 (Prof Chris Gale)
498 QQ 85, 88 (Prof James Boardman); UCL, 'Overview of the EPICure studies': https://www.ucl.ac.uk/womens-health/research/neonatology/epicure/overview-epicure-studies [accessed 16 September 2024]
499 Q 89 (Prof James Boardman)
500 Q 69 (Prof Chris Gale); Written evidence from Prof Nicola Doherty (PRT0078)
501 RAND, *Pregnancy research review*, pp 7, 23: https://www.rand.org/pubs/research_reports/RR4340.html [accessed 15 July 2024]
502 The Medical Research Council is part of UK Research and Innovation (UKRI), a non-departmental public body sponsored by the Department for Science, Innovation and Technology (DSIT). UKRI, 'About UK Research and Innovation' https://www.ukri.org/who-we-are/about-uk-research-and-innovation/ [accessed 15 July 2024]
503 RAND, *Pregnancy research review*, p 8: https://www.rand.org/pubs/research_reports/RR4340.html [accessed 15 July 2024]

on cardiovascular disease alone in the same period".[504] Prof MacIntyre underlined that research on perinatal health and preterm birth represented only "a small fraction of that".[505]

228. Dr Jessica Boname, Interim Head of Population and Systems Medicine at MRC, told us that its funding for preterm birth research has "averaged about £4.6 million per annum over the last five years". She acknowledged that these funding levels had been "rather static". Across perinatal health research more generally, however, MRC's funding increased from £7.5 million in 2018–19 to £13 million in 2022–23.[506] Professor Lucy Chappell, Chief Executive Officer at NIHR and Chief Scientific Adviser at DHSC, set out that, over the last five years, NIHR has invested in 77 research awards, representing £93 million of funding across the projects' full duration. These "range across a whole portfolio" of pregnancy research areas, including preterm birth prevention.[507]

229. We heard that the lack of industry investment in pregnancy research and treatment development exacerbates funding shortages.[508] Dr Aiken told the Committee that "only two new drugs have been approved globally and licensed anywhere for pregnancy-specific conditions in the last 30 years".[509] Professor Neena Modi noted that "there has only ever been one medicine ever developed specifically for a neonatal condition, surfactant."[510] Professor Anna David, Professor in Obstetrics and Maternal Fetal Medicine at University College London, suggested that the pharmaceutical industry is "interested in doing drugs trials, but finds it very difficult, because it is incredibly risky for it to invest in them".[511]

230. Witnesses called for an increase in funding across all areas of pregnancy research, as well as for investigations focused on the causes, prevention and management of preterm birth specifically.[512] Professor Jon Dorling, Academic Consultant Neonatologist at University Hospital Southampton NHS Trust, suggested that having focused calls for perinatal and neonatal research from funding bodies would be beneficial.[513] However, Dr Boname suggested that it would be "unfair" for funding bodies to tell the research community "what we need to spend our money on."[514]

231. Prof Chappell noted the role of the James Lind Alliance in identifying evidence gaps and medical research priorities.[515] Its most recent list of priorities for preterm birth was published in 2014.[516] Prof Chappell also highlighted that

504 Nature, 'Women's health research lacks funding—these charts show how' [May 2023]: https://www.nature.com/immersive/d41586-023-01475-2/index.html [accessed 16 September 2024]
505 Q 66 (Prof David MacIntyre)
506 Q 231 (Dr Jessica Boname)
507 Q 261 (Prof Lucy Chappell)
508 Q 66 (Prof Mark Johnson, Prof David MacIntyre, Prof Sarah Stock)
509 Q 46 (Dr Catherine Aiken)
510 Written evidence from Prof Neena Modi (PRT0037)
511 Q 67 (Prof Anna David)
512 Q 66 (Prof Anna David, Prof David MacIntyre, Prof Sarah Stock); Written evidence from British Maternal and Fetal Medicine Society (PRT0008), Bliss (PRT0063) and Royal College of Obstetricians and Gynaecologists (PRT0072)
513 Q 103 (Prof Jon Dorling)
514 Q 232 (Dr Jessica Boname)
515 Q 262 (Prof Lucy Chappell)
516 James Lind Alliance, 'Preterm birth: Top 10 priorities': https://www.jla.nihr.ac.uk/priority-setting-partnerships/preterm-birth#tab-28056 [accessed 15 October 2024]

the National Institute for Health and Care Research (NIHR)[517] has recently launched its first ever 'challenge', with a specific focus on inequalities in maternity care. DHSC explained:

> "This funding call, backed by £50 million, will task researchers and policymakers with finding new ways to tackle maternity disparities by bringing together a diverse consortium, funding research and capacity building".[518]

Baroness Merron, Parliamentary Under-Secretary of State for Patient Safety, Women's Health and Mental Health, suggested that the case for public funding of research was being made as part of work towards the 2025–26 spending review.[519]

Research capacity

232. Dr Boname highlighted that the success rate of applications to the MRC for preterm birth-related research is higher than average (35% compared to around 20%). She added: "we fund excellent research when it comes in, but we do not receive that many applications."[520]

233. Prof Johnson suggested that this may be due to the limited number of people working in the field.[521] Prof MacIntyre told the Committee that the limited funding for this area of research may be creating a "brain drain", as junior academics move into other areas of medical research that offer greater financial security.[522]

234. Witnesses also highlighted the significant decline in the number of clinical academics in recent years, an issue that is being reviewed by the Office for Strategic Coordination of Health Research.[523] Prof Boardman called for NHS trusts to support their workforce to partner in research activities.[524] Louise Wren, Director of External Affairs at Association of Medical Research Charities, argued that research should be seen "as a critical part of the NHS", and that staff involved in research should have protected time for this work.[525]

Insurance and regulation

235. We heard from Prof David that it can be very difficult to secure insurance for pregnancy-related clinical trials.[526] Insurers are concerned about the risk of high litigation costs yet struggle to assess these risks given that so few trials are conducted, leading to disproportionate premiums.[527] A 2022 policy commission led by Birmingham Health Partners proposed a model of "co-insurance with Government" in the short term. It argued this would

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517 NIHR is the largest funder of pregnancy research in the UK and is part of the Department of Health and Social Care. RAND, *Pregnancy research review*, p 8: https://www.rand.org/pubs/research_reports/RR4340.html [accessed 15 July 2024]; UKRI, 'About UK Research and Innovation' https://www.ukri.org/who-we-are/about-uk-research-and-innovation/ [accessed 15 July 2024]
518 Written evidence from Department of Health and Social Care (PRT0081)
519 Q 261 (Baroness Merron)
520 Q 231 (Dr Jessica Boname)
521 Q 66 (Prof Mark Johnson)
522 Q 66 (Prof David Macintyre)
523 Q 89 (Prof James Boardman), Q 232 (Dr Jessica Boname) and Q 233 (Louise Wren)
524 Q 89 (Prof James Boardman)
525 Q 233 (Louise Wren)
526 Q 65 (Prof Anna David)
527 Written evidence from Tommy's (PRT0057)

overcome the "'chicken-and-egg' situation", by generating clinical trial activity data that would then enable insurers to develop a risk framework.[528]

236. Prof Boardman noted a similar issue, clinical trials presenting potential risks to the patient, as a challenge facing neonatal research: "[there is] an unjustified bias among ethics committees and regulatory bodies towards excluding neonates from studies." He suggested that neonatal research is often seen as too difficult and ethically challenging, and recommended improving the representation of perinatologists on ethics committees and funding panels.[529]

Data

237. Professor Alexander Heazell, Professor of Obstetrics, University of Manchester, also highlighted the importance of data availability for research: "We cannot emphasise strongly enough the value of the neonatal research database and the fact that we do not have the same thing in maternity services." He added that, when evaluating the implementation and impact of SBLCB version two, they had intended to use the maternity services dataset to evaluate it but "the quality of data in the system was simply not good enough."[530] Dr Jenny Carter, Research Midwife at King's College London, suggested that this was because "each trust has control over the procurement of its IT systems" and called for "top-down procurement for the NHS completely, so that everyone uses the same system."[531] Dr Angharad Care agreed. She also noted that there are "inconsistencies with the skill mix of people inputting this data" and a "lack of quality assurance."[532]

238. Prof Boardman called for improved international data exchange, potentially through regulatory bodies becoming more aligned. He suggested that international research collaboration is necessary to enable the researchers to run clinical trials at the scale required to "demonstrate the safety and efficacy of a new intervention".[533]

239. Prof Dorling argued that there are "issues and challenges" with sharing data more generally, as well as joining different datasets together, which is making research more difficult.[534] Professor Sam Oddie, National Clinical Lead at National Neonatal Audit Programme, agreed: "If I could get this committee to do one thing, it would be to advocate for better linkage between maternity and neonatal routinely collected data … We have the data; it is just not joined up."[535]

240. **Research is an essential component of optimising care and outcomes for mothers at risk of preterm birth and babies who are born prematurely. A greater focus on pregnancy and neonatal research is needed, alongside increased funding, to make progress in understanding the fundamental mechanisms of preterm labour, developing more effective interventions, and ensuring clinical guidance is implemented effectively.**

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528 University of Birmingham, *Healthy Mum, Healthy Baby, Healthy Future* (May 2022), p 15: https://www.birminghamhealthpartners.co.uk/wp-content/uploads/2022/05/Final-Healthy-Mum-Healthy-Baby-Healthy-Future-Report-AW_Accessible-PDF-REDUCED-FILE-SIZE.pdf [accessed 16 September 2024]
529 Q 90 (Prof James Boardman)
530 Q 144 (Prof Alexander Heazell)
531 Q 144 (Dr Jenny Carter)
532 Written evidence from Dr Angharad Care (PRT0039)
533 Q 89 (Prof James Boardman)
534 Q 100 (Prof Jon Dorling)
535 Q 103 (Prof Sam Oddie)

APPENDIX 1: LIST OF MEMBERS AND DECLARATIONS OF INTEREST

Members of the Preterm Birth Committee

Baroness Blackstone (from 7 March 2024)
Viscount Colville of Culross
Baroness Cumberlege
Lord Hampton
Baroness Hughes of Stretford (from 14 February 2024)
Lord Patel
Baroness Owen of Alderley Edge
Baroness Seccombe
Baroness Thornhill (until 20 May 2024)
Baroness Watkins of Tavistock
Lord Winston
Baroness Wyld

Declarations of interests

Baroness Blackstone
Chair of Trustees, Royal College of Obstetricians and Gynaecologists

Viscount Colville of Culross
No relevant interests to declare

Baroness Cumberlege
No relevant interests to declare

Lord Hampton
No relevant interests to declare

Baroness Hughes of Stretford
No relevant interests to declare

Baroness Owen of Alderley Edge
No relevant interests to declare

Lord Patel
Professor Emeritus of Obstetrics, University of Dundee
Fellow, Academy of Medical Sciences
Fellow, Royal College of Obstetricians and Gynaecologists
Fellow, Royal Society of Edinburgh

Baroness Seccombe
No relevant interests to declare

Baroness Thornhill
No relevant interests to declare

Baroness Watkins of Tavistock
Fellow, Royal College of Nursing
Registered Nurse (non-practising)
Non-executive Director, NHS England

Lord Winston
Professor Emeritus of Fertility Studies, Imperial College London
Fellow, Academy of Medical Sciences
Fellow, Royal College of Physicians
Fellow, Royal College of Obstetricians and Gynaecologists
Fellow, Royal Society of Biology
Chairman, Genesis Research Trust
Advisor, Essential Parent Company Ltd

Current research grants assessing human embryonic metabolism

Baroness Wyld

Non-executive Board Member, Ofsted

Member of the Court, University of Newcastle upon Tyne

A full list of members' interests can be found in the Register of Lords' Interests: https://members.parliament.uk/members/lords/interests/register-of-lords-interests

Specialist adviser

Dr Eleri Adams

Consultant Neonatologist, Oxford University Hospitals NHS Foundation Trust

President, British Association of Perinatal Medicine

National Neonatology Specialty Lead, Getting It Right First Time (GIRFT) programme, NHS England

APPENDIX 2: LIST OF WITNESSES

Evidence is published online at: https://committees.parliament.uk/committee/701/preterm-birth-committee/publications/ and available for inspection at the Parliamentary Archives (020 7219 3074).

Evidence received by the Committee is listed below in chronological order of oral evidence session and in alphabetical order. Those marked with ** gave both oral and written evidence. Those marked with * gave oral evidence and did not submit any written evidence. All other witnesses submitted written evidence only.

Oral evidence in chronological order

*	Dr Jennifer Jardine, Academic Clinical Lecturer in Obstetrics and Gynaecology, Queen Mary University of London	QQ 1–16
*	Professor Marian Knight MBE, Professor of Maternal and Child Population Health, and Director, National Perinatal Epidemiology Unit, University of Oxford	QQ 1–16
*	Professor Jan van der Meulen, Professor of Clinical Epidemiology, London School of Hygiene and Tropical Medicine, and Chair, National Maternity and Perinatal Audit Project Team	QQ 1–16
*	Clea Harmer, Chief Executive, Sands	QQ 17–29
**	Kath Abrahams, Chief Executive, Tommy's	QQ 17–29
*	David Badcock, Chief Executive, Borne	QQ 17–29
*	Dr Catherine Aiken, Associate Professor and Honorary Consultant in Fetal and Maternal Medicine, Cambridge University Hospitals	QQ 30–49
**	Professor Asma Khalil, Professor of Obstetric and Maternal Fetal Medicine, St George's Hospitals	QQ 30–49
**	Caroline Lee-Davey, Chief Executive, Bliss	QQ 50–61
**	Ciara Curran, Founder, Little Heartbeats	QQ 50–61
**	Catriona Ogilvy, Founder and Chair, The Smallest Things	QQ 50–61
*	Professor Anna David, Professor in Obstetrics and Maternal Fetal Medicine, University College London	QQ 62–67
*	Professor Mark Johnson, Clinical Chair in Obstetrics, Imperial College London	QQ 62–67
*	Professor David MacIntyre, Professor of Reproductive Systems Medicine, Imperial College London	QQ 62–67
*	Professor Sarah Stock, Professor of Maternal and Fetal Health, University of Edinburgh	QQ 62–67
*	Dr Sarah Bates, Consultant Paediatrician and Neonatologist, Great Western Hospitals NHS Trust	QQ 68–75

*	Professor David Edwards, Professor of Paediatrics and Neonatal Medicine, King's College London	QQ 68–75
*	Professor Chris Gale, Professor of Neonatal Medicine, Imperial College London	QQ 68–75
*	Professor James Boardman, Professor of Neonatal Medicine, University of Edinburgh	QQ 76–105
*	Professor Jon Dorling, Academic Consultant Neonatologist, University Hospital Southampton NHS Trust	QQ 76–105
*	Professor Sam Oddie, Consultant Neonatologist, Bradford Teaching Hospitals NHS Foundation Trust, and National Clinical Lead, National Neonatal Audit Programme	QQ 76–105
*	Professor Stavros Petrou, Professor of Health Economics, Nuffield Department of Primary Care Health Sciences, University of Oxford	QQ 106–121
**	Professor Elaine Boyle, Professor of Neonatal Medicine and LCFC Professor in Child Health, University of Leicester	QQ 106–121
**	Hilary Cruickshank, Clinical Specialist Neonatal Physiotherapist, NHS Lothian, and Chair, British Association for Neonatal Neurodevelopmental Follow-up	QQ 122–134
**	Professor Samantha Johnson, Professor of Child Development, University of Leicester	QQ 122–134
**	Professor Neil Marlow, Emeritus Professor of Neonatology, University College London	QQ 122–134
*	Professor Alex Heazell, Professor of Obstetrics, University of Manchester	QQ 135–148
**	Dr Jenny Carter, Research Midwife, King's College London	QQ 135–148
**	Professor Neena Modi, Professor of Neonatal Medicine, Imperial College London	QQ 135–148
*	Dr Sundeep Harigopal, Clinical Lead, Northern Neonatal Network	QQ 149–165
*	Kelly Harvey, Senior Lead Nurse, North West Neonatal Operational Delivery Network	QQ 149–165
*	Professor Lawrence Impey, Clinical Lead, Thames Valley Maternity and Fetal Medicine Network	QQ 149–165
*	Professor Andrew Shennan OBE, Professor of Obstetrics, King's College London	QQ 166–179
*	Professor Judith Stephenson, Professorial Researcher and Honorary Consultant in Public Health/Sexual and Reproductive Health, University College London	QQ 166–179

**	Clare Livingstone, Professional Policy Adviser, Royal College of Midwives	QQ 180–193
**	Róisín McKeon-Carter, Chair, Neonatal Nurses Association	QQ 180–193
**	Professor Basky Thilaganathan, Spokesperson, Royal College of Obstetricians and Gynaecologists and Clinical Director, Tommy's National Centre for Maternity Improvement	QQ 180–193
*	Dr Martine Jeukens-Visser, Research Associate, Amsterdam University Medical Center	QQ 194–205
*	Professor John Newnham, Chair, Australian Preterm Birth Prevention Alliance and Professor of Obstetrics and Gynaecology, University of Western Australia	QQ 194–205
*	Professor Mikael Norman, Professor in Paediatrics and Neonatal Medicine, Karolinska Institute	QQ 194–205
*	Francesca Segal, author of *Mother Ship*	QQ 206–213
**	Nadia Leake, author of *Surviving Prematurity*	QQ 206–213
*	Caroline Lacy, LMNS Clinical Programme Lead, NHS Somerset ICB	QQ 214–229
*	Catherine McClennan, Director of Women's Health and Maternity Programme and LMNS Senior Responsible Officer, NHS Cheshire and Merseyside ICB	QQ 214–229
*	Sam Pretlove, Deputy Chief Medical Officer, Birmingham Women and Children's NHS Foundation Trust and NHS Birmingham and Solihull ICB	QQ 214–229
*	Dr Jessica Boname, Interim Head of Population and Systems Medicine, Medical Research Council	QQ 230–238
*	Louise Wren, Director of External Affairs, Association of Medical Research Charities	QQ 230–238
*	Professor Jonathan Benger CBE, Chief Medical Officer and Interim Director of the Centre for Guidelines, NICE	QQ 239–243
*	Dr Clare Morgan, Director of Implementation and Partnerships, NICE	QQ 239–243
*	Kate Brintworth, Chief Midwifery Officer, NHS England	QQ 244–253
*	Professor Donald Peebles, National Clinical Director for Maternity, NHS England	QQ 244–253
**	Professor Lucy Chappell, Chief Scientific Adviser, Department of Health and Social Care	QQ 254–265
**	Baroness Merron, Parliamentary Under-Secretary of State for Patient Safety, Women's Health and Mental Health, Department of Health and Social Care	QQ 254–265

**	Fiona Walshe, Director of Mental Health, Disabilities and Maternity, Department of Health and Social Care	QQ 254–265

Alphabetical list of witnesses

**	Kath Abrahams, Chief Executive, Tommy's (QQ 17–29)	PRT0057
	Action Cerebral Palsy	PRT0006
	Action on Smoking and Health	PRT0077
	Joanne Adams	PRT0036
	Adult Preemie Advocacy Network	PRT0066
*	Dr Catherine Aiken, Associate Professor and Honorary Consultant in Fetal and Maternal Medicine, Cambridge University Hospitals (QQ 30–49)	
	Anonymous	PRT0002
	Anonymous	PRT0007
	Anonymous	PRT0009
	Anonymous	PRT0014
	Anonymous	PRT0015
	Association for Improvements in Maternity Services	PRT0038
	Association of Directors of Public Health	PRT0086
	Nicole Au	PRT0075
*	David Badcock, Chief Executive, Borne (QQ 17–29)	
*	Dr Sarah Bates, Consultant Paediatrician and Neonatologist, Great Western Hospitals NHS Trust (QQ 68–75)	
	Dr Jasper Been	PRT0033
*	Professor Jonathan Benger CBE, Chief Medical Officer and Interim Director of the Centre for Guidelines, NICE (QQ 239–243)	
	Amina Berour	PRT0046
*	Professor James Boardman, Professor of Neonatal Medicine, University of Edinburgh (QQ 76–105)	
*	Dr Jessica Boname, Interim Head of Population and Systems Medicine, Medical Research Council (QQ 230–238)	
**	Professor Elaine Boyle, Professor of Neonatal Medicine and LCFC Professor in Child Health, University of Leicester (QQ 106–121)	PRT0027
*	Kate Brintworth, Chief Midwifery Officer, NHS England (QQ 244–253)	
	British Association of Perinatal Medicine	PRT0042
	British Maternal and Fetal Medicine Society	PRT0008

	Sarah Brooks	PRT0055, PRT0062
	Dr Angharad Care	PRT0039, PRT0068
	Care Quality Commission	PRT0041, PRT0085
**	Dr Jenny Carter, Research Midwife, King's College London (QQ 135–148)	PRT0053
	Helen Cater	PRT0036
	Cepheid UK	PRT0064
	Dr Fiona Challacombe	PRT0058
**	Professor Lucy Chappell, Chief Scientific Adviser, Department of Health and Social Care (QQ 254–265)	PRT0081
	CHEM Trust	PRT0025
	Professor Paul Christiansen	PRT0054
	CLOSER (UCL)	PRT0023
	Dr Rachel Collum	PRT0016, PRT0031
**	Hilary Cruickshank, Clinical Specialist Neonatal Physiotherapist, NHS Lothian, and Chair, British Association for Neonatal Neurodevelopmental Follow-up (QQ 122–134)	PRT0070
**	Ciara Curran, Founder, Little Heartbeats (QQ 50–61)	PRT0082
*	Professor Anna David, Professor in Obstetrics and Maternal Fetal Medicine, University College London (QQ 62–67)	
	Joanne Deery	PRT0043
	Professor Nicola Doherty	PRT0078
*	Professor Jon Dorling, Academic Consultant Neonatologist, University Hospital Southampton NHS Trust (QQ 76–105)	
*	Professor David Edwards, Professor of Paediatrics and Neonatal Medicine, King's College London (QQ 68–75)	
	Ei SMART CIO	PRT0024
	ESMI II Research Team	PRT0071
	Dr Victoria Fallon	PRT0054
	Dr Filippos Filippidis	PRT0033
	Emma Foulerton	PRT0036
	Dr Caroline Fox	PRT0005
	Maria Furtado	PRT0036

*	Professor Chris Gale, Professor of Neonatal Medicine, Imperial College London (QQ 68–75)	
	Professor Camilla Gilmore	PRT0017
	Ruth Goh	PRT0033
	Dr Lauren Goodfellow	PRT0013
	Nadia Griffin	PRT0079
*	Dr Sundeep Harigopal, Clinical Lead, Northern Neonatal Network (QQ 149–165)	
*	Clea Harmer, Chief Executive, Sands (QQ 17–29)	
	Catherine Hart	PRT0048
	Denise Hart	PRT0036
*	Kelly Harvey, Senior Lead Nurse, North West Neonatal Operational Delivery Network (QQ 149–165)	
	Health Equity North	PRT0044
	Health Innovation West of England	PRT0011
	Lady Sarra Hoy	PRT0031
	Human Fertilisation and Embryology Authority	PRT0084
	Gillian Ingledow	PRT0012
	Lauren Ingledow	PRT0016, PRT0065
*	Professor Lawrence Impey, Clinical Lead, Thames Valley Maternity and Fetal Medicine Network (QQ 149–165)	
	Institute of Health Visiting	PRT0083
	International Fetal and Newborn Growth Consortium for the 21st Century	PRT0040
*	Dr Jennifer Jardine, Academic Clinical Lecturer in Obstetrics and Gynaecology at Queen Mary University of London (QQ 1–16)	
*	Dr Martine Jeukens-Visser, Research Associate, Amsterdam University Medical Center (QQ 194–205)	
*	Professor Mark Johnson, Clinical Chair in Obstetrics, Imperial College London (QQ 62–67)	
**	Professor Samantha Johnson, Professor of Child Development, University of Leicester (QQ 122–134)	PRT0017, PRT0018, PRT0027
	Kent, Surrey and Sussex Neonatal Operational Delivery Network	PRT0061
**	Professor Asma Khalil, Professor of Obstetrics and Maternal Fetal Medicine, St George's Hospital, University of London (QQ 30–49)	PRT0054

*	Professor Marian Knight MBE, Professor of Maternal and Child Population Health at Oxford University (QQ 1–16)	
	Aman Kumar	PRT0035
*	Caroline Lacy, LMNS Clinical Programme Lead, NHS Somerset ICB (QQ 214–229)	
	Dr Anthony Laverty	PRT0033
**	Nadia Leake, author of *Surviving Prematurity* (QQ 206–213)	PRT0069
**	Caroline Lee-Davey, Chief Executive, Bliss (QQ 50–61)	PRT0063
	Leeds Teaching Hospitals NHS Trust	PRT0003
**	Clare Livingstone, Professional Policy Adviser, Royal College of Midwives (QQ 180–193)	PRT0051
	Anna Lukens	PRT0036
*	Professor David MacIntyre, Professor of Reproductive Systems Medicine, Imperial College London (QQ 62–67)	
*	Catherine McClennan, Director of Women's Health and Maternity Programme and LMNS Senior Responsible Officer, NHS Cheshire and Merseyside ICB (QQ 214–229)	
	Dr Rachel McFarland	PRT0068
	Dr Liz McKechnie	PRT0069
**	Róisín McKeon-Carter, Chair, Neonatal Nurses Association (QQ 180–193)	PRT0074
	Dr Catherine McParlin	PRT0049
	Professor Brad Manktelow	PRT0027
**	Professor Neil Marlow, Emeritus Professor of Neonatology, University College London (QQ 122–134)	PRT0018
	Abigail Mason-Woods	PRT0026
**	Baroness Merron, Parliamentary Under-Secretary of State for Patient Safety, Women's Health and Mental Health, Department of Health and Social Care (QQ 254–265)	PRT0081
*	Professor Jan van der Meulen, Professor of Clinical Epidemiology at London School of Hygiene and Tropical Medicine (QQ 1–16)	
	Dr Louise Michie	PRT0049
	Professor Christopher Millett	PRT0033
**	Professor Neena Modi, Professor of Neonatal Medicine, Imperial College London (QQ 135–148)	PRT0037
	Professor Ben Mol	PRT0075

*	Dr Clare Morgan, Director of Implementation and Partnerships, NICE (QQ 239–243)	
	Gemma Morgan	PRT0068
	National Child Mortality Database	PRT0060
	Neonatal Dietitians Group	PRT0020
	Neonatal Leads for Psychological Practice in England	PRT0052
	Networks Neonatal Outreach Group	PRT0022
*	Professor John Newnham, Chair, Australian Preterm Birth Prevention Alliance and Professor of Obstetrics and Gynaecology, University of Western Australia (QQ 194–205)	
	NIHR ARC West	PRT0056
	NIHR Children and Families Policy Research Unit	PRT0034
*	Professor Mikael Norman, Professor in Paediatrics and Neonatal Medicine, Karolinska Institute Sweden (QQ 194–205)	
*	Professor Sam Oddie, Consultant Neonatologist, Bradford Teaching Hospitals NHS Foundation Trust, and National Clinical Lead, National Neonatal Audit Programme (QQ 76–105)	
**	Catriona Ogilvy, Founder and Chair, The Smallest Things (QQ 50–61)	PRT0032
	Parent Advisory Group for East of England Neonatal Operational Delivery Network	PRT0050
	Dr Alex Patience	PRT0049
*	Professor Donald Peebles, National Clinical Director for Maternity, NHS England	QQ 244–253
	PERIScope Team	PRT0016
	Dr Lucinda Perkins	PRT0073
*	Professor Stavros Petrou, Professor of Health Economics, Nuffield Department of Primary Care Health Sciences, University of Oxford (QQ 106–121)	
*	Sam Pretlove, Deputy Chief Medical Officer, Birmingham Women and Children's NHS Foundation Trust and NHS Birmingham and Solihull ICB (QQ 214–229)	
	Professor Maria Quigley	PRT0059
	Phillipa Ranson	PRT0036
	Queen Mary University of London	PRT0028
	Resuscitation Council UK	PRT0076
	Helen Robinson	PRT0036
	Royal College of Obstetricians and Gynaecologists	PRT0072

	Royal College of Occupational Therapists	PRT0067
	Royal College of Speech and Language Therapy Clinical Excellence Network	PRT0047
	Katherine Sabin	PRT0058
	Sands and Tommy's Joint Policy Unit	PRT0045
	Dr Sarah Seaton	PRT0027
*	Francesca Segal, author of *Mother Ship* (QQ 206–213)	
*	Professor Andrew Shennan OBE, Professor of Obstetrics, King's College London (QQ 166–179)	
	Sergio A. Silverio	PRT0054
	Society for the Protection of Unborn Children	PRT0019
	South Tyneside and Sunderland NHS Foundation Trust	PRT0001
	Spoons	PRT0021
	Jessica Srivastava	PRT0075
	Rachel Stamp	PRT0036
*	Professor Judith Stephenson, Professorial Researcher and Honorary Consultant in Public Health/Sexual and Reproductive Health, University College London (QQ 166–179)	
*	Professor Sarah Stock, Professor of Maternal and Fetal Health, University of Edinburgh (QQ 62–67)	
	Suffolk and Northeast Essex Local Maternity and Neonatal System	PRT0080
*	Professor Basky Thilaganathan, Spokesperson, Royal College of Obstetricians and Gynaecologists and Clinical Director, Tommy's National Centre for Maternity Improvement (QQ 180–193)	
	Twins Trust	PRT0030
	UK National Screening Committee	PRT0004
**	Fiona Walshe, Director of Mental Health, Disabilities and Maternity, Department of Health and Social Care (QQ 254–265)	PRT0081
	Professor Dieter Wolke	PRT0010
	Semra Worrall	PRT0054
*	Louise Wren, Director of External Affairs, Association of Medical Research Charities (QQ 230–238)	
	Charlotte Xanthadis	PRT0036

APPENDIX 3: CALL FOR EVIDENCE

The House of Lords Preterm Birth Committee was appointed in January 2024. It is chaired by Lord Patel and will report by 30 November 2024.

Aim of the inquiry

Preterm birth—when a baby is born before 37 weeks of pregnancy—is the single biggest cause of neonatal mortality and morbidity in the UK. Just under 8% of live births are preterm each year. The Government has set an ambition to reduce the preterm birth rate to 6% of live births by 2025.

The Committee will focus on the prevention, and consequences, of preterm birth in England. There are a wide range of risk factors associated with preterm birth but in many cases the cause is unknown. This inquiry will examine how preterm births can be prevented and how the adverse consequences of preterm birth for mothers, babies and families can be reduced.

It will assess whether current Government policy is adequate and how to close the gap in outcomes among women and babies from different backgrounds. This will include looking at primary and secondary prevention, neonatal care, and longer-term support for preterm babies and their families.

This is a public call for written evidence to be submitted to the Committee. The deadline is 5.00pm on Wednesday 27 March 2024.

Instructions on how to submit evidence are set out below. If you have any queries please email the staff of the Committee at hlpretermbirth@parliament.uk.

When preparing your response, please keep in mind that short, concise submissions are preferred. Written evidence must be relevant to the points set out below, but you do not need to address every topic.

Topics

The Committee is seeking written submissions addressing any or all of the following topics:

Variation in care and health inequalities

- The implementation of existing NICE and NHS guidance on preterm birth.
- The ethnic and socioeconomic inequalities seen in relation to preterm birth and how these could be reduced.

Prevention

- The screening and prediction of preterm birth, including through the use of new technologies.
- Primary prevention and treatment for preterm birth.
- Secondary prevention and treatment for preterm birth.

Neonatal and longer-term care and support

- How neonatal care can improve outcomes for babies born preterm.
- How postnatal care and psychological support for women who have given birth preterm and parents can improve outcomes.

- Integration between neonatal care for babies born preterm and postnatal care for women.
- Longer-term impacts, care and support for preterm babies and their families.

Other topics

- Research and development to prevent preterm birth and improve care for babies and mothers.
- Learnings from the devolved administrations and other countries around the world.

We understand that the issues raised in this work may be sensitive or upsetting. The following organisations may be able to offer support or further information:

Bliss

Bliss provides support for parents and families of premature or sick babies.

Website: https://www.bliss.org.uk/

Sands

Sands supports anyone affected by pregnancy loss or the death of a baby and offers a wide range of bereavement support.

Website: https://www.sands.org.uk/

Phone: 0808 164 3332

Tommy's

Tommy's provides a free information service about health in pregnancy, plus bereavement support for anyone who has experienced a pregnancy loss.

Website: https://www.tommys.org/

Phone: 0800 0147 800

APPENDIX 4: NOTE ON THE COMMITTEE'S VISIT TO CHELSEA AND WESTMINSTER HOSPITAL

On 16 April 2024, the Committee visited the neonatal unit at Chelsea and Westminster Hospital in London. Members in attendance were:

- Viscount Colville of Culross
- Lord Hampton
- Baroness Owen of Alderley Edge
- Lord Patel.

The hospital is part of the Chelsea and Westminster Hospital NHS Foundation Trust. It provides all levels of neonatal care for the geographical area it serves.

The Committee was given a tour of three clinical areas—the intensive care unit, the high dependency care unit and the special care unit—and the facilities available to parents and family members. During the visit, Committee members spoke with healthcare professionals and representatives of the hospital's senior leadership team, as well as parents whose babies were receiving care on the neonatal unit.

APPENDIX 5: GLOSSARY

Arabin pessary	A soft silicone ring that is inserted into the vagina and positioned so that the cervix sits inside it, with the aim of helping to keep the cervix closed
BAPM	British Association of Perinatal Medicine
Cervical cerclage	A stitch that is placed around the cervix, with the aim of helping to keep the cervix closed. The stitch is inserted either vaginally, or through the abdomen
Cervical length scan	An ultrasound scan through the vagina, abdomen or perineum, used to measure the length of the cervix during pregnancy
Delayed cord clamping	Delaying the clamping of a baby's umbilical cord until at least 60 seconds after birth
DHSC	Department of Health and Social Care
Fetal fibronectin	A protein that helps to keep the amniotic sac attached to the lining of the uterus during pregnancy. It can be detected in cervicovaginal secretions throughout pregnancy, with levels typically remaining low between 22 and 35 weeks
Fetal fibronectin test	Used to determine the level of fetal fibronectin in a sample of vaginal fluid. Higher concentrations are associated with an increased risk of preterm delivery
Gestational age	A term used to describe how far along a pregnancy is in weeks at the time of birth
ICB	Integrated care board. Has responsibility for planning and funding most NHS services in the geographical area that it covers
ICS	Integrated care system. Brings together organisations including local government, integrated care boards and the voluntary sector to develop health and care strategies for the area that it covers
Live birth	A birth where the baby shows signs of life, regardless of gestational age
LMNS	Local maternity and neonatal system. Brings together purchasing bodies, hospital trusts and service users to provide and improve maternity and neonatal care
LNU	Local neonatal unit. Provides short-term intensive care, as well as high dependency and special care for babies and families in the local population
MIS	Maternity Incentive Scheme
MMN	Maternal medicine network. Group of NHS providers, based in the same geographical area, that work together to provide specialist antenatal and postnatal care for women with complex medical conditions

Neonatal death	A death which occurs within the first 28 days of life
NICE	National Institute for Health and Care Excellence
NICU	Neonatal intensive care unit. Provides all levels of neonatal care
NIHR	National Institute for Health and Care Research
NMPA	Neonatal Maternity and Perinatal Audit
NNAP	National Neonatal Audit Programme
ODN	(Neonatal) operational delivery network. Group of NHS providers, based in the same geographical area, that work together to ensure that care is delivered in a co-ordinated way across different types of neonatal unit
PPROM	Preterm prelabour rupture of membranes
Progesterone	A hormone that can prevent contractions and help a pregnancy continue to term. Given during pregnancy as a tablet that is inserted into the vagina or rectum
RCOG	Royal College of Obstetricians and Gynaecologists
RCM	Royal College of Midwives
SBLCB	Saving Babies' Lives Care Bundle
SCU	Special care unit. Provides special and transitional care for babies and families in the local population
Stillbirth	A birth after 24 completed weeks of pregnancy where the baby shows no signs of life