Briefing on Sands response to the NHS Change Consultation - December 2024

Executive Summary

In Autumn 2024, the Government announced the largest ever consultation on the future of the NHS. Submissions will help to inform the new 10-year plan for the future of the NHS which is expected to be published in Spring 2025.

We are calling for a safer, personalised maternity system in England which sets ambitious targets to reduce baby deaths and save babies' lives. The scale of pregnancy and baby loss is not inevitable. We must see action taken to reduce preventable baby deaths and better support for bereaved parents when a baby does die, with NHS trusts supported by the Government to fully implement the National Bereavement Care Pathways in England.

What are Sands calling for to be included in the 10-year plan?

Renew and extend the national maternity safety ambitions

The 10-year plan must renew the national maternity safety ambitions between 2025-2035, with ambitious targets to save babies' lives.

The Sands and Tommy's Joint Policy Unit are proposing the following ambitions to replace the existing national maternity safety ambitions, with a deadline of 2035 to align with the 10 Year Plan for the NHS in England:

- A stillbirth rate of 2.0 stillbirths per 1,000 total births.
- A neonatal mortality rate of 0.5 neonatal deaths per 1,000 live births for babies born at 24 weeks' gestation and over.
- A preterm birth rate of 6.0% by 2035, with disaggregated data for iatrogenic and spontaneous preterm births.
- Eliminate inequalities in these outcomes based on ethnicity and deprivation.
- Establishing routine data collection on miscarriages should be prioritised. Once established, an ambition to reduce the miscarriage rate should be added.

Improved quality and safety of maternity services

The 10-year plan must set out a comprehensive national approach that supports improvement across all maternity and neonatal services.

The current scale of baby loss is not inevitable. In 2022-23, 1 in 5 baby deaths may have been prevented with better care which equates to 800 babies'. Maternity safety must be given the time, attention and focus it requires, including implementation and oversight of recommendations from national maternity reports, evaluating the effectiveness of current policy interventions and ensuring care is always delivered in line with nationally agreed standards.

Ending inequality in baby loss

The 10-year plan must include a new National Maternity Safety Ambition to end inequalities in baby loss by closing the mortality gap by ethnicity and deprivation.

In 2022, Black babies were over twice as likely to be stillborn compared with white babies – and Asian babies were almost 50% more likely to be stillborn. Black and Asian babies are over 50% more likely to die shortly after birth compared with white babies.

The stillbirth rate in the most deprived areas of the UK is double that of the least deprived. MBRRACE-UK's state of the nation report, published in July 2024, found that in 2022, 'the difference in neonatal mortality rates between the least deprived and most deprived quintiles is now the highest it has been since 2017.'

It is essential that renewed national maternity safety ambitions include a focus on ending inequality in baby loss.

Improved mental health support for bereaved families

The 10-year plan must ensure that any parent who has suffered pregnancy or baby loss and needs high-quality specialist psychological support can access it free of charge, at a time and place that is right for them, wherever they live

In 2019, the Baby Loss Alliance published *Out of Sight, Out of Mind*. 60% of bereaved parents told us they could not access the specialist psychological support they needed through the NHS. In the same year, the Government announced Maternal Mental Health Services (MMHSs) to fill the gap between community and perinatal mental health services. We were pleased these included specific pathways for pregnancy and baby loss.

MMHSs are now available in most areas of England. A recent report by the Maternal Mental Health Alliance found all services who responded to a request for information had specific pathways for pregnancy and baby loss.

However, we know that support for bereaved parents (particularly for fathers and partners) remains patchy across England with unacceptably long waiting lists and a lack of specialist staff.

A fully implemented National Bereavement Care Pathway (NBCP)

All hospitals must be supported by NHS England and NHS trust leadership to fully implement the NBCP standards, including funding for specialist bereavement staff, training and bereavement spaces. Once implemented, NHS England must audit provision against the NBCP standards regularly.

Whilst all hospitals in England have agreed to adopt the NBCP standards, it is essential that they are supported by NHS England to properly implement them. This will require NHS England and NHS trust leadership to support maternity staff in implementing the standards and for Government to provide the necessary funding. CQC reports have identified some hospitals with bereavement rooms which are not compliant with the NBCP standard as they are not soundproofed. Implementing these changes will require investment to enable hospitals to comply.

Supporting bereaved parents throughout reviews and investigations

The current complaints and reviews process is unnecessarily complicated for bereaved parents to navigate. NHS England should place a positive obligation on healthcare professionals to facilitate bereaved parents raising their concerns. The continuing existence of 'blame culture' prevents openness and transparency with bereaved parents. The complaints and regulatory landscape of maternity services must be simplified.

When something does go wrong, parents must get answers about what happened, and steps must be taken by all healthcare professionals to ensure lessons are learnt to prevent it happening again.

Moving care from the hospital into the community

The Sands and Tommy's Joint Policy Unit have said that service design must be based on clear evidence as to how it meets the needs of women and babies – rather than fitting into a general policy ambition for the NHS to move care into the community. For some aspects of maternity and neonatal care, access to specialist high-quality care in a hospital environment is vital.

Maternity safety

All women and birthing people must have access to high quality antenatal care in the community or hospital, with clear, evidence-based advice on the different options available to them. Barriers to this advice being made available must be removed, for example the absence of interpretation and translation services.

Whether triage is completed in the community or hospital, it is essential that nationally agreed standards are introduced for triage systems to ensure consistency.

Bereavement care

High quality bereavement care will often begin in the hospital, under the guidance of specialist bereavement staff, but following discharge this moves into the community.

More must be done to break the narrative that pregnancy and baby loss is something which happens and can't be prevented. Whilst outside the scope of the 10-year NHS plan, there needs to be a cross-departmental approach to supporting employers to recognise pregnancy and baby loss and provide bereavement support to parents. Supporting bereaved parents in the community may begin with primary healthcare workers but should be everyone's concern.

Technology

Perinatal pathology – minimally invasive post-mortem

Following the loss of a pregnancy or death of a baby, a post-mortem may help to identify what happened and provide answers for parents. Delays in receiving post-mortem results can be detrimental to parents' mental health.

The opportunities presented by advancements in technology allowing for minimally invasive post-mortem may help to reduce the amount of time parents are waiting for results. Investment must be made in rolling out this technology to all regions in England.

NHS digital systems

Different NHS systems do not always communicate with one another or flag that a pregnancy or baby loss has occurred to other services, such as GPs, dentists or physiotherapists.

This means bereaved parents must explain what has happened multiple times. This is unacceptable. Technology must enable all NHS providers to be informed when a patient has experienced pregnancy or baby loss.

Translation and Interpretation

It is imperative that there are no barriers to parents receiving medical advice or bereavement support such as the absence of translation and interpretation services.

All notes and records must be able to be translated if English is not a person's first language. NHS trusts must also consider how complaints and investigations by NHS trusts are translated and interpreted to parents who may not speak or write in English as their first language.

Prevention

Preventable baby deaths

We know that 1 in 5 baby deaths may have been prevented with better care. It is essential that nationally agreed standards of care are delivered by all NHS trusts, including implementation of the Saving Babies' Lives Care Bundle V3.

More research is needed. Despite significant progress in healthcare, the cause of death in one third of stillbirths is still unknown, 15 in every 100 pregnancies ends in miscarriage and 13 babies a day die before, during or shortly after birth. If medical professionals are equipped with the knowledge of why these deaths happen and have more effective interventions this will save babies' lives.

Bereavement care

We are also aware that across different NHS trusts there are varying levels of specialist bereavement midwife cover. Whilst some hospitals have, or are aiming, to implement 24/7 cover others find it difficult to cover a seven-day service during working hours.

Pregnancy and baby loss is something which can happen at any time. It is important that bereavement care begins in the hospital as this is the opportunity for memory making and for decisions to be made about post-mortems and burial/cremation. It is essential that there are trained bereavement staff available 24/7 to ensure this can happen.

Contact about this briefing: campaigns@sands.org.uk