Written evidence submitted by Sands UK (MSE0008)

Safety of maternity services in England

Submission from Sands – the stillbirth and neonatal death charity

1 Bulleted summary of the key points in our submission

"The NHS must do better - it is full of caring individuals but the system itself needs to improve."
Bereaved parent

Every day in the UK around 14 babies die before, during or soon after birth. Baby deaths need to fall much faster if the English government's National Maternity Safety Ambition to reduce deaths by 50% by 2025 is to be achieved.

To make the UK one of the safest places in the world to have a baby, we need to understand which initiatives are working on the ground, which actions remain outstanding from previous inquiries, and what support hospitals need to provide the safest care possible.
We must also join up disparate initiatives to create an effective early warning system. The UK is a world leader in gathering data about baby deaths and in recent years we have seen a focus on improving learning through perinatal investigations and reviews. But these varied sources of data have not been brought together in a systematic way to inform wider system changes, to help identify outlier Trusts early, or to pin point those reforms which are having the greatest impact.

We must focus on systems change, including the support NHS Trusts need to embed and sustain improvements. To do this we must to move away from a culture of denial and blame, and instead incentivise candour, support improvements, and systematically revisit recommendations to ensure sustained change.

Sands believes that this inquiry is of fundamental importance, coming mid-way through the period of the national ambition and a year before the Maternity Transformation Programme is due to end. Not only must the inquiry help us to evaluate the impact of existing reforms, but it must lead to a more robust and integrated safety system which is embedded for the future.

Recommendations

a) We need an integrated maternity safety system that identifies problems early and supports NHS Trusts to improve:
    i. **Early Warning System (missing).** This should bring together evidence from the CQC, MBRRACE, PMRT, HSIB and the CNST. It would need clear oversight from an accountable organisation. Thought needs to be given as to which organisation could best fulfil that role?
    ii. **Investigation when something goes wrong (in place).** Findings from reviews and investigations must be shared with all front line staff. Evidence that views have been sought from parents must be provided.
    iii. **Follow up to see that recommendations have been acted upon and data shows improvement (missing).** This needs to happen at both national and local levels.

b) All data submissions from local Trusts must be monitored in an appropriate and robust way, with an element of external scrutiny.
c) Funding is required both to deliver training and to pay for cover for staff who attend.
d) An expanded programme of perinatal confidential enquiries should be established, at least two per year, to provide understanding of what changes are needed in the delivery of care.
e) All PMRT review panels must include genuinely independent membership by having an external member from outside the Trust
f) Parents should have a formal opportunity to challenge the PMRT report if they disagree with the findings, with an appeals process
g) The implementation of PMRT reviews must be fully resourced within NHS Trusts.
h) Independent investigations into all maternity incidents that meet the EBC reporting criteria must continue and expand to encompass term antepartum stillbirths.
i) All reviews must include a process by which learning is disseminated locally (SMART action plan which reaches front line practitioners) and across the system.
j) As well as publishing an annual review, pulling together key themes from all of the maternity investigations undertaken during the year to identify learning and ensure systemic change, HSIB should conduct a minimum of two thematic investigations into maternity services each year, co-ordinated with MBRRACE-UK to build on emerging themes from local investigations.
k) Data to understand baby deaths must be rapidly available and used to improve care and prevent deaths. This must include mandatory rapid notification of all stillbirths to bring this into line with reporting of neonatal deaths.
l) MBRRACE-UK must be exempted from the NHSE national data opt out.
m) The impact of perinatal mortality on BAME communities needs to be better understood, with a target to reduce inequalities in outcomes established.
n) Review the experience of BAME families using maternity services to better understand the impact of implicit bias
o) Update guidance to reflect that safeguarding actions should be followed in the context of public health measures such as lockdown.
p) A successor to the Maternity Transformation Programme, which includes service-user voice, must be put in place.

2 Introduction to Sands

This submission is from Sands, the stillbirth and neonatal death charity. We work across the UK to support anyone affected by the death of a baby, improve the care that parents receive from the NHS and to reduce the number of babies dying.

Sands has invested over £1,000,000 in perinatal research projects, are partners in the MBRRACE-UK[1] collaboration and support a range of national maternity safety initiatives, including the Maternity Transformation Programme[2]. We are involved in the development of the Perinatal Mortality Review Tool (PMRT). Sands also leads the National Bereavement Care Pathway[3], with over 90% of all English Trusts having now registered an interest. We regularly provide training and guidance to NHS Trusts.

In 2018, as well as running over 100 local peer support groups, more than 270,300 people accessed Sands resources online. We reached 2,000,000 people through our website and social media. Over 27,800 healthcare professionals accessed Sands' bereavement care resources. We are currently

[1] https://www.npeu.ox.ac.uk/mbrrace-uk
[2] https://www.england.nhs.uk/mat-transformation/
[3] https://nbcpathway.org.uk/

providing tailored support to bereaved parents within both the Shrewsbury and Telford and the East Kent NHS Trusts.

3 What the impact has been of the work which has already taken place aimed at improving maternity safety, and the extent to which the recommendations of past work on maternity safety by Trusts, Government and its arm's-length bodies, and reviews of previous maternity safety incidents, are being consistently and rigorously implemented across the country?

Impact of improvement work

"I feel I was kept fully informed by the consultants, midwives & anaesthetists throughout my induction, labour, delivery and post-natal care. This was a vital part in allowing me to feel like I had a voice & say in my care." Bereaved parent

Since the publication of Better Births and the formation of the Maternity Transformation Programme some progress has been made. Rates of stillbirths and neonatal deaths have fallen but not by nearly enough to meet the target to halve them by 2025. We must at least double the rate every year between now and 2025 if we are to meet the target.

The MBRRACE-UK collaboration collects information about all late fetal losses, stillbirths, neonatal deaths and maternal deaths. Taking data from hospitals, the programme monitors changes in maternal and baby deaths year by year, identifying NHS Trusts where rates are higher or lower than expected. It looks at causes of death and at risk factors such as ethnicity. This information, and the Confidential Enquiries also undertaken by MBRRACE-UK, have been vital in improving care in recent years.

However, returns and notifications are not made fast enough by some Trusts leading to a time lag in the potential for national monitoring to identify where mortality is higher than expected, and losing the opportunity to take early action. Without any independent check on the quality and accuracy of data provided by Trusts there is concern from parents that their version of what happened is not reflected in the data MBRRACE-UK receives. Perinatal confidential enquiries, which have been demonstrated to be rich in learning, only take place once every two years, rather than annually as is the case for the far smaller number of maternal deaths.

The NHS England Saving Babies' Lives Care Bundle version two[4] brings together four vital aspects of safer care to reduce stillbirth, early neonatal death and pre term birth. Evaluation of the first iteration of the Care Bundle showed a 20% fall in stillbirth rates in participating Trusts, as well as an impact on NHS resourcing. However we know that not all aspects of the Care Bundle are being implemented rigorously and consistently on the ground. There is too much variation and the Coronavirus pandemic has shown that these reforms are vulnerable, likely to be dropped in times of crisis without adequate risk-assessment, and with the concern they may not fully resume.

A number of reforms, including the Safer Maternity Care National Action Plan, have been made to the way in which reviews and investigations into baby deaths are undertaken. These are discussed in the next section.

There is evidence that women who receive continuity of carer have a better experience, with women who received midwife-led continuity of care less likely to experience preterm birth, or to

[4] https://www.england.nhs.uk/wp-content/uploads/2019/07/saving-babies-lives-care-bundle-version-two-v5.pdf

lose their baby in pregnancy or in the first month following birth. However, the NHS has faced significant challenges in implementing this important reform.

There have been reviews into standards of maternity care in individual trusts. It is depressing to see the same issues coming up time and again. We desperately need action to change the culture that enables these failures to reoccur, as well as a mechanism that ensures that progress on key recommendations is independently reviewed on a regular basis.

Bereaved parents experiences

"Women who are considered low risk should not be overlooked in a busy system." Bereaved parent

Evidence gathered by Sands on the experiences of bereaved parents, shows that maternity reforms are not embedded on the ground. Our survey of bereaved parents experiences of maternity and neonatal care[5] showed:

- Women are not receiving continuity of carer from pregnancy into labour
- A third of parents felt unable to raise concerns they had about their baby, or if they did raise them, they felt their concerns were not taken seriously
- Many women are getting different messages about what care they need from different staff
- Low risk at booking does not mean no risk, with only 35% of the women whose baby died in this survey considered high risk from the start of pregnancy
- 40% of women were concerned about the level of care they received in pregnancy, feeling that the right tests and monitoring were not carried out in a timely way
- Too many parents are not aware of hospital mortality reviews, and did not know if their baby's care had been investigated
- The majority women (70%) were satisfied everything possible had been done for their baby around their birth.

Systemic changes needed

"Despite being well informed about my pregnancy risks, our concerns were almost totally dismissed with disastrous results. My son did not deserve to die." Bereaved parent

Given the plethora of new initiatives and guidance, combined with the enormous pressure the Coronavirus pandemic has put on the NHS, now is the time to step back and look at system-wide reforms.

Currently reforms are fragmented, variably implemented and resources are stretched and not reaching areas of greatest need. There are different underlying reasons, including the lack of a systems-wide approach, the blame-culture in some Trusts, a lack of robust monitoring and under-use (and linkage) of the available data.

Investigation is currently the only one of the three steps needed for a safer maternity system, with the first and last steps as set out below missing:

a. **Early Warning System (missing).** This should bring together evidence from the CQC, MBRRACE, PMRT, HSIB and the CNST. It would need clear oversight from an accountable organisation and thought needs to be given to which would best fulfil that role.

[5] https://www.sands.org.uk/professionalsprofessional-resources/sands-survey-maternity-and-neonatal-care-findings

b. **Investigation when something goes wrong (in place).** Findings from reviews and investigations must be shared with all front line staff. Evidence that views have been sought from parents must be provided.
c. **Follow up to see that recommendations have been acted upon and data shows improvement (missing).** Needs to happen at both national and local level.

To achieve the missing elements we must:

- Identify a clear responsible body with oversight
- Set out an escalation process with clear trigger points so that problems are identified and acted on early
- Inspire a culture of openness, support and lessons learning, with embedded service improvement which is monitored
- Prioritise NHS staff wellbeing with support and training
- Have a clear pathway for parents so they can navigate what can be multiple investigation processes, and contribute if they wish.
- Provide opportunities to quality check reviews by comparing findings of different investigations on the same baby

4 The contribution of clinical negligence and litigation processes to maternity safety, and what changes could be made to clinical negligence and litigation processes to improve the safety of maternity services

"It has taken two and a half years for the hospital to accept clinical negligence. Our concerns were not heard during labour or after labour. A 6 day labour with 13 contacts and two admissions and we still ended up with a dead baby because no one was listening." Bereaved parent

Without a culture of openness and no-blame, mistakes and system errors will continue to be down-played or even covered up by Trusts that are incentivised to demonstrate infallibility. This needs to be tackled at every level, from clinical training, to management ethos, to resource allocation. We need a system that applauds honesty and transparency, highlighting what needs to change.

An open learning culture across maternity care is not embedded everywhere so it is no surprise that litigation threats and blame deter clinicians from looking honestly and constructively at where things have gone wrong. The burden falls on parents when litigation is their only option for finding answers.

We need to refine the Clinical Negligence Scheme for Trusts (CNST). The concept of a financial incentive to change behaviour is evidence-based. However, while the scheme is good in theory it is poorly implemented in practice. The self-reporting element of this scheme is inherently flawed and must be changed. Financial incentives can drive improvement but the current iteration of the CNST scheme is too often driving cover-up as resource-strapped Trusts strive to avoid financial penalties.

The scheme will only work effectively if it is joined up with other safety assurance work in maternity. Compliance with the schemes needs to be more robustly monitored with independent verification that trusts have carried out the ten maternity safety actions.
There is a need to move away from a culture of 'compliance tick boxes' to a balance of mechanisms that check staff are competent, and have the resources and working framework they need, to deliver safe care.

5 Advice, guidance and practice on the choices available to pregnant women about natural births, home births and interventions such as C-sections, and the extent to which medical advice and decision-making is affected by a fear of the "blame culture

"*After my baby died I was told by the obstetrician and the bereavement midwife that the reason my baby died was because I decided to try a vaginal breech birth instead of having a c section. It was very hard to be told it was my fault that my baby died. I made a decision based on the information I had available. I made a birth choice and I thought the hospital would support me and keep me safe. I was always clear that if at any time my baby was as in danger I would then agree to have a c section but his heart rate was not monitored properly. Every day I think about the events that caused my baby's death and I wish more than anything I could change what happened. I hope things improve in the future."*
Bereaved parent.

Personalised care is safe care and the choices available and appropriate for each woman need to be discussed in the context of what is right for the individual. Information for pregnant women needs to be consistent, without bias, based-on NICE/RCOG guidance, and written according to Plain English guidance.

6 How effective the training and support offered to maternity staff is, and what improvements could be made to them to improve the safety of maternity services

"It is vital that midwives are told never to assume all is ok and never to make the mother feel like she is wasting time as a result of this assumption." Bereaved parent

We recognise the need for more training for staff working in maternity services especially in human factors, Cardiotocography (CTG) measures, fetal heart rate and uterine contractions, staff resilience and wellbeing, obstetric emergencies, communication skills, and, learning from adverse events.

Maternity safety training should also include personalised care for bereaved parents. Sands training offers professionals the opportunity to develop their skills in this area.

Cultural competency training is required to ensure all maternity staff can better respond to women's needs. Systematic reviews have shown that the behaviours of healthcare providers can contribute to health disparities. The National Maternity Review showed that women from different backgrounds felt healthcare professionals needed to understand and respect their cultural and personal circumstances (NHS England, 2016b). Training is important to understand cultural perceptions of stillbirth in BAME communities so that advice is tailored to dispel myths.

Training alone is not enough. Poor care also arises when staff do not have access to the latest national guidance or where local guidelines have not been updated. A national tool for assessing staff competency is required to ensure that all staff are safe and competent in the above areas.

Finally, funding is required both for training delivery and to pay for cover for staff who attend. We hear from staff regularly that they find it difficult to get funding and time away from work to attend training.

7 The role and work of the Healthcare Safety Investigation Branch in improving the safety of maternity services, and the adequacy and appropriateness of the collection and analysis of data on maternity safety
Investigations and reviews

"It was appalling. I now have zero faith in the NHS. It's hard to when even senior consultants are embarrassed and shocked at the events that happened around our daughter's death and crucially the care that followed." Bereaved parent

One-third of stillborn babies, around 1,200 babies every year, die after a full-term pregnancy (37 or more weeks) when a baby has the greatest chance of surviving. Within this, every year around 250 babies die right at the end of pregnancy from an intrapartum-related event.

We need a joined-up system that helps us to learn from the deaths of babies, understand what needs to change, and, prevent future tragedies.

Current processes for reviews and investigations are in their infancy. For bereaved parents and families the system is complex, opaque and all too often lacking in human empathy. Time and again bereaved parents tell Sands that they want answers about why their baby died. If something went wrong, they want an apology, to be listened to and for the death of their baby to have made a difference.

We need a responsive system that encourages hospitals to identify systemic problems and which supports them to improve their practice where this is needed. But we also need a transparent and fair system, which meets the needs of bereaved parents and families to understand what has happened to their baby and so that they have faith that moving forward lessons will be learned.

The Perinatal Mortality Review Tool (PMRT) provides the framework to enable hospitals to undertake high quality, consistent reviews into their own care. But the tool can only be effective if the Trust ensures external scrutiny in the review process. Staff must have the time and resources to conduct the review to the standards the PMRT lays out.

Sands believes all PMRT review panels must include genuinely independent membership by having an external member from outside the Trust. The first annual report of the PMRT, published in October 2019, found that less than 10% of reviews involved an external member[6].

There must also be measures in place to ensure that parents are supported to genuinely engage in the review (if they wish) and that learning from these reviews is disseminated and implemented by front line practitioners.1 Parents must have a formal opportunity to challenge the PMRT report if they disagree with findings, with an appeals process.

Role of HSIB

In addition to this, it is vital that robust, independent investigations continue for term deliveries, as we know that these babies have the best chance of surviving.

In 2017, the Safer Maternity Care National Action Plan set out new measures to improve the rigour and quality of investigations into term stillbirths, serious brain injuries and deaths of mothers and babies. The HSIB maternity investigations had only just begun to report before the pandemic struck. Given this, Sands believes that our recommendations (below) are best achieved by adapting and improving current arrangements, rather than introducing yet another body/new process into this complex framework.

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[6] https://www.npeu.ox.ac.uk/assets/downloads/pmrt/reports/PMRT%20Report%202019%20-%20Executive%20Summary.pdf

- To ensure that internal hospital reviews into stillbirths and neonatal deaths are of the highest quality, implementation of the PMRT must be fully resourced within NHS Trusts. Funding is required to ensure local reviews are robust, that the right people are in the room, and, to support parental engagement.
- Independent investigations into all maternity incidents that meet the EBC reporting criteria must continue, and expand to encompass term antepartum stillbirths.
- Any system for independent maternity investigations must meet the following criteria[7]:
    - Every baby's care should be investigated robustly by a team that includes staff from different professions (midwives, doctors, anaesthetists etc.), with staff given time off from normal duties so they can take part.
    - Parents should be told that a review is taking place and invited to take part if they would like to
    - Reviews should involve a healthcare professional from outside the team/Trust who can give an independent perspective
    - Reviews should spend more time looking at problems with systems (the way things are done in the Unit/Ward) than at individual staff.
- All reviews must include a process by which learning is disseminated locally (SMART action plan which reaches front line practitioners) and across the system.
- There must be a named body with responsibility for setting the framework for maternity investigations, including quality assurance.
- A consistent parent/family pathway must be established to guide families through the process.
- As well as publishing an annual review, pulling together key themes from all of the maternity investigations undertaken during the year to identify learning and ensure systemic change, HSIB should conduct a minimum of two thematic investigations into maternity services each year, co-ordinated with MBRRACE-UK to build on emerging themes from local investigations.

Collection and analysis of data on maternity safety

"Mistakes were made through lack of reading my notes. Certain questions were not asked that could have prevented our preterm labour. This is frustrating. All hospitals, GPs etc. should follow the same procedure." Bereaved parent

At Sands we also believe the Government could do more, using MBRRACE, CQC, PMRT, HSIB, CSNT and ONS data to understand baby deaths in England and ensure progress towards reducing baby deaths by 50% by 2025. We know that rates have not be falling at a uniform rate across the board and that more needs to be done to understand which babies are dying in the perinatal period and why. Drawing data sources together, ensuring more rapid notifications, undertaking data analysis and modelling could feed in to an early warning system to highlight areas where action is required to improve the safety of care before crisis point is reached.

There is currently a discrepancy between the reporting of stillbirths and neonatal deaths. Neonatal deaths must be reported straight away, with Ministers receiving weekly reports from the National Child Mortality Database. There is no such stipulation for stillbirths. This means that there is an unacceptable lag in reporting of stillbirths to MBRRACE-UK.

There is also a threat to the future of MBRRACE audits, confidential enquiries and the PMRT. Changes to the rules about sharing data from patient records could put these programmes in jeopardy. All NHS patients in England can choose whether data from their confidential health

[7] These were the initial criteria proposed by the Each Baby Count's team

records can be shared for research and planning. The choice is either: yes to all sharing, or no any sharing. There is no middle choice.

The MBRRACE-UK programme does not yet have special exemption from data opt out. This means that in September 2020 when new rules come in, MBRRACE will not be told about a baby's death if the mother has opted-out of data sharing for her own medical records, which include everything about her baby. If data about some baby deaths are missing from the information sent to MBRRACE-UK, it will become impossible to carry out meaningful monitoring of baby deaths in England. We believe that the programme must be granted special exemption to ensure this vital monitoring continues.

8 Inequalities

"Looking back now, the care pre my daughter's death wasn't great. But how do you know when you've never been pregnant before?" Bereaved parent

The government must urgently work to ensure that babies are not at a higher risk of death simply because of their parents' postcode, ethnicity or income.

Compared with white babies, stillbirth rates for Black/Black British babies are twice as high, and, for Asian/Asian British babies they are 1.6 times as high. For babies from the most deprived families, stillbirth rates are 1.7 times higher than from the least deprived.

We have known about health inequalities in relation to maternity outcomes for over 70 years, yet we still have no evidence-based interventions to reduce these risks. With reports about racism in the NHS it seems likely that care in maternity is not always as equal as it should be. This is uncomfortable but needs to be looked at. We need to hear from BAME women about their experiences and what could be done better.

Interventions to provide culturally appropriate services to the targeted populations should increase the uptake of services, particularly attendance at antenatal appointments. To achieve this we need to review the experience of BAME families using maternity services and better understand the impact of implicit bias.

We must use the existing research evidence to develop quality improvement programmes, which are in turn rolled out and evaluated. For example, we need to better understand the reasons for the current poor interaction some groups of women have with healthcare professionals and to improve professionals' ability to provide information and support in a way that is helpful for BAME women. Considering how best to provide information to BAME communities is important to empower women and families to manage their health, especially where stigma remains about the causes of stillbirth. A joined up approach involving policymakers, politicians, religious leaders and local communities will be essential.

Health promotion information must recognise ethnic and cultural diversity. NHS maternity services have focussed on reaching out to diverse communities in targeted communications over the past few months, but this approach needs to be evaluated and embedded.

Health inequalities relating to stillbirth had been gradually narrowing, but we fear this may reverse under the pandemic. We have heard that BAME women are particularly fearful of engaging with hospitals and NHS services during the pandemic. Inequalities in access to digital technologies means that the growing delivery of appointments and services on-line may be disadvantaging some women.

Domestic abuse

Up to 60% of pregnant women experience domestic abuse[8]. Women experiencing domestic abuse are at higher risk of pregnancy and baby loss. Our helpline is now receiving a growing number of calls relating to domestic abuse with women often finding it difficult to access support (which has been exacerbated under social distancing measures). Guidance must be updated to reflect that safeguarding actions should be followed in the context of public health measures such as lockdown.

9 Impact of COVID and what this means

"Even before I fell pregnant I had anxiety surrounding falling pregnant again due to what happened with my daughter. I voiced these to many medical professionals who promised me they would closely monitor me and do all they could to protect my unborn baby yet my monitoring was called off early as the "risk of catching covid outweighed the benefit to come to hospital" yet exactly what COULD have happened to my baby DID happen to my baby." Bereaved parent

During the COVID 19 pandemic, Sands has been working to support pregnant women, bereaved families and NHS staff, as well as to ensure that maternity and neonatal care remains as safe as possible. As we have extended our support, an increasing number of people have raised safety issues with us:

- Women's concerns about reduced fetal movements were not acted on, with some women either told not to come in to hospital or turned away when they arrived. In some of these cases the baby died.
- Some blood, urine, growth checks, scans and other antenatal appointments were cancelled, with these services reclassified as low priority.
- Some women were too fearful of the virus to attend hospital.
- Medical care for women following the loss of a pregnancy or baby was absent.
- Second trimester losses were badly managed with women being sent home to cope alone without adequate information.
- Women had to give birth to their dead babies alone and without access to a bereavement suite.
- MBRRACE notifications of deaths were not made in a timely way and reviews following the death of a baby were not carried out.

Since the initial crisis, we have seen clear messaging from Royal Colleges and NHS England encouraging pregnant women to get in touch with their midwives, to attend appointments, and to report any concerns that they might have about their pregnancy.

However, from the information we have received to date, we fear that the COVID 19 pandemic may result in more babies dying both now and into the future. While the impact of the virus itself on perinatal morality appears to be small, there has been a profound impact on the delivery of maternity safety initiatives.

As recovery plans are put into place and we return to a new normal, we must ensure that the importance of maintaining (and improving) standards of maternity safety are placed firmly on NHS Trust agendas. The pandemic has highlighted the fragility of many core safety initiatives and their vulnerability to being dropped during times of crisis. Trust Boards must be incentivised to prioritise maternity and neonatal safety, these services are not an optional extra but a core component of a

[8] *https://www.bestbeginnings.org.uk/domestic-abuse*

safe and personalised NHS. A successor to the Maternity Transformation Programme, including service user voice, must be put in place.

7 September 2020