Written evidence submitted by Sands and Tommy's Joint Policy Unit (PSN0023)

The Sands and Tommy's Joint Policy Unit is focussed on achieving policy change that will save more babies' lives during pregnancy and the neonatal period and on tackling inequalities in loss, so that everyone can benefit from the best possible outcomes.

We welcome the opportunity to make a written submission to inform the Health and Social Care Committee's Independent Expert Panel in their evaluation of public inquiry/review recommendations on patient safety which have been accepted by the Government.

We have provided responses to recommendations that the committee is evaluating in the following three areas:

- Maternity care and leadership
- Training of staff in health and social care
- Culture of safety/whistleblowing

Policy area - Maternity care and leadership

Recommendation 1: ***"There is no mechanism to scrutinise perinatal deaths or maternal deaths independently, to identify patient safety concerns and to provide early warning of adverse trends. This shortcoming has been clearly identified in relation to adult deaths by Dame Janet Smith in her review of the Shipman deaths, but is in our view no less applicable to maternal and perinatal deaths, and should have raised concerns in the University Hospitals of Morecambe Bay NHS Foundation Trust before they eventually became evident. Legislative preparations have already been made to implement a system based on medical examiners, as effectively used in other countries, and pilot schemes have apparently proved effective. We cannot understand why this has not already been implemented in full, and recommend that steps are taken to do so without delay***." **(Morecambe Bay Investigation, 2015)**

Importance of reviews and investigations following the death of a baby

When serious incidents occur, it is important to have an independent, standardised method of investigating. The National Perinatal Mortality Review tool (PMRT) supports objective, robust and standardised hospital reviews of care. The Maternity and Newborn Safety Investigations (MNSI) programme (formerly the Healthcare Safety Investigation Branch (HSIB), carries out independent investigations of maternity and neonatal incidents, meeting certain criteria.

Perinatal Mortality Review Tool (PMRT)

The PMRT provides the framework to enable hospitals to undertake high quality, consistent reviews into their own care. To meet the requirements of the Maternity Incentive Scheme, Trusts in England are required to use the PMRT to review perinatal deaths and create action plans for improvement.

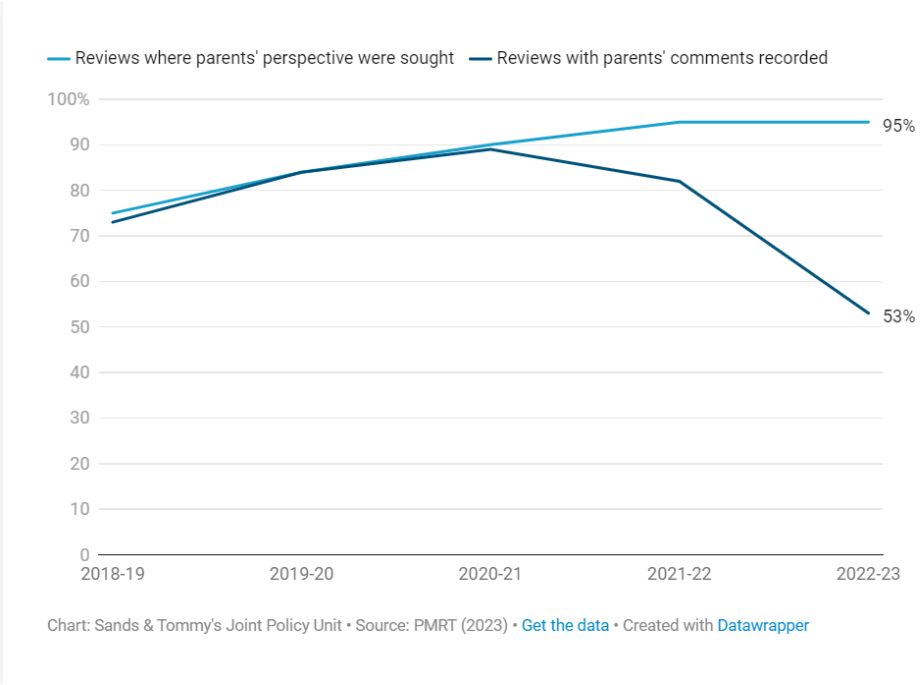
Quality of reviews:

- Sufficient resourcing and leadership commitment are required to deliver thorough reviews and develop strong action plans to improve practice.
- Despite an increasing amount of information being collected and reviews carried out, the reviews are not being used effectively enough by the health system to support improvements.
- In its 2023 annual report, the PMRT rated 49% of action plans as 'weak' and only 14% as 'strong' in 2022-23. The proportion of action plans rated 'strong' declined in the most recent report, from 19% in 2021-22. Strong actions are "system level changes which remove the reliance on individuals to choose the correct action. They use standardisation and permanent physical or digital designs to eliminate human error".
- There is limited external oversight and accountability of reviews led by hospitals where deaths occurred. Quality of the review is influenced by the availability of relevant information, a larger, multi-disciplinary team undertaking the review (including a neonatologist or paediatrician), parents' involvement, and external involvement.
- MBRRACE recently published confidential enquiries into Black and Asian baby deaths in 2019. The enquiry reviewed the PMRT review alongside their own independent analysis and found that many reviews were carried out by only one doctor or midwife instead of a group, or by a small group without enough of the right specialists.
- There have been some high-level improvements in reviews since it was introduced - the median number of staff present has increased from five in 2018-19 to eight in 2021-22 and 84% of reviews had a neonatologist or paediatrician present in 2022-23, compared to 59% in 2018-19.
- Two-thirds (66%) of reviews in 2022-23 did not include an external panel member. Having a relevant professional who is external to the trust / health board is recommended by the PMRT collaboration to provide "fresh eyes" and an independent perspective on the care that was given.
- PMRT reviews provide an overall grading of care which indicates the extent to which improvements to care may have affected the outcome (ie. prevented the death of the baby). Over time, there has been a decrease in the proportion of reviews where no issues with care were identified and an increase in reviews that found that care may have affected the outcome. While the improvements outlined above suggest that this change may be due to better quality reviews rather than declining quality of care, without further external analysis it is not possible to differentiate between the two.

- The MBRRACE confidential enquiries found that hospital reviews were more positive than the conclusions reached by the confidential enquiry panels. Although improvements have been made since these reviews in 2019, this independent analysis suggests that the number of deaths which could have been avoided with better care may be higher than the 1 in 5 currently estimated by the PMRT.

Engaging families in reviews:

- The PMRT has highlighted the continued need for greater parent engagement in reviews. There must be measures in place to ensure that parents are supported to genuinely engage in the review, including a formal way of challenging the PMRT report if they disagree with findings, with an appeals process.
- The PMRT's latest report suggests improvements in parents' engagement. 95% of reviews sought parents' perspectives in 2022-23, compared to 75% in 2018-19. The graph below shows parents' engagement has steadily increased over time, however, there has been a decline in the number of reviews with parents' comments recorded:



- Sands research has found that while some parents describe a positive experience, others report poor communication, delays, and explanations about their baby's death which still leaves them with questions. 1 in 5 parents surveyed by Sands did not understand what the review entailed which limited their ability to engage in the process. 34% of parents said they did not receive answers, either because they were unaware of the review (11%) or because they took part in the review, but it did not provide any answers (23%).

Sharing learnings from the PMRT:

As well as providing answers to parents and families, it is vital that the learnings from reviews and investigations are shared and acted upon, to prevent avoidable deaths in the future. In addition to being used at board level, insight from reviews must be used nationally. Currently, information from the PMRT does not feed into a wider national system for improving safety. The recent investigations into maternity services at Shrewsbury and Telford and East Kent Trusts have highlighted that there is still a way to go in organisations holding themselves to account for the action they are taking to learn from serious incidents.

HSIB reviews (now MNSI)

In 2018, HSIB established its maternity programme to conduct independent and standardised investigations into maternity care. In October 2023 this became the Maternity and Newborn Safety Investigation programme (MNSI) which is hosted by the Care Quality Commission.

Findings from evaluations:

- There is some evidence to suggest a positive impact: evaluations show staff feel more listened to, and that HSIB has taken a broader view of cases by including services outside of maternity, in comparison to trust investigations. National Maternity Indicators show some improvement in organisations integrating learnings. 8 out of 10 midwives feel their organisation takes action so similar errors and near misses do not happen again.
- Crucially, family engagement has also improved: data from HSIB indicates that 88% of families engaged with HSIB's investigations during 2019–20, compared with 34% of families in trust investigations.
- Despite some progress, there continues to be issues around timeliness of investigations, and ensuring lessons from serious incidents are integrated into future delivery. Concerns have been raised about there being no way of enforcing change once HSIB has reached a conclusion in an investigation. There are also clear issues around differing accounts of events between families and staff. Without an agreed understanding of what happened, learning is often missed.
- There has been concerns raised about the culture within the organisation, with allegations of bullying: Allegations of bullying within maternity programme of the Healthcare Safety Investigation Branch – Channel 4 News

It is essential that concerns are addressed in the move to the MNSI programme hosted by the CQC. In particular that reviews are robust, engage compassionately and effectively with families, and ensure robust actions are taken when issues in care identified. It is essential that recommendations made following a review are followed up and audited to ensure necessary changes have been made.

The pandemic highlighted the fragility of many core safety initiatives, with Maternity Transformation Programme initiatives being suspended. MBRRACE notifications of deaths were not made in a timely way and reviews following the death of a baby were not carried out. It is important that we learn lessons from the pandemic and the vulnerability of safety initiatives to be dropped during times of crisis.

Coronial investigations and the crisis in perinatal pathology

In 2019 the Ministry of Justice and Department of Health and Social care jointly ran a public consultation on the coronial investigation of stillbirths. A factual summary of the consultation responses was published in December 2023, which stated that the government was still exploring the issues raised as well as ongoing issues which impact on decisions whether to take forward proposals in the short term, including the current crisis in perinatal pathology.

There is an urgent need to address the crisis of perinatal pathology in England, as discussed in this briefing on the issue from Sands. Currently, a significant proportion of parents must wait over three to six months for their baby's post-mortem to be undertaken and for the results to be communicated to them. This is having a devastating impact on parents, leaving them in distressing limbo, unable to move on with their grief, and lacking important information which can determine difficult decisions about another pregnancy.

The shortage of perinatal pathologists has been growing over decades. In most recent years mutual aid between pathology centres reduced the impact on national delivery of services, but that approach is breaking down as overburdened centres have dwindling capacity to pick up cases beyond their own area.

Some initiatives to improve the situation, including a recruitment drive and plans to use new technologies, are ongoing but will take significant time to have an impact. It is important that the Government provide additional resources and support to ensure that the needs of bereaved parents are being prioritised.

Recommendation 2: "*A common code of ethics, standards and conduct for senior board-level healthcare leaders and managers should be produced and steps taken to oblige all such staff to comply with the code and their employers to enforce it.*" (From the Report of the Mid Staffordshire NHS Foundation Trust Public Inquiry, 2013.)

Trust board responsibility for safety and quality of services

As providers of services, the safety and quality of maternity and neonatal services are ultimately the responsibility of Trust boards. Trust leadership at the executive and board level is reviewed by the CQC during inspections. However, failures in board leadership continue to be identified in reviews and inquiries. The Kirkup review of maternity and neonatal services in East

Kent found that, among other issues, the Trust board missed several opportunities to properly identify the scale and nature of problems and to put them right.

Sands and Tommy's Joint Policy Unit have recently published a report highlighting issues with the oversight that NHS Trust boards have over the safety and quality of maternity and neonatal services. The aim of this research was to review whether the information presented to boards - and subsequent review and discussion – enabled boards to deliver on their responsibility of ensuring the safety and quality of their service.

Some of the key findings in our report were:

- Boards are not consistently being presented with the key metrics which NHS England has suggested to provide an overview of maternity and neonatal service performance. This, along with data being spread over multiple reports with little to no additional analysis to draw attention to declining metrics or trends, limits their capability to have full oversight over their service.
- Board members may not have full understanding of the data being shared. Clinical service leaders have the knowledge to contexualise data and help board members to understand the implications. However, from the reports we reviewed it appeared that this knowledge was not currently translating into the submissions to the board.
- Trust boards review information from across the Trust which makes focusing on particular services challenging. Agendas only allocated between 5–30 minutes to discuss maternity services. Discussion notes showed variable scrutiny from board members, suggesting limited capacity for boards to comprehend and explore insights fully.
- Inconsistencies with metrics being reported on, a lack of contexualised intelligence and limited discussions and scrutiny of data suggests that the current board reporting process may not be leading to the effective insights needed for board members to maintain full oversight of their services.

Policy area - Training of staff in health and social care

Recommendation 1: *"Targeted interventions on collaborative leadership and organisational values, including a new, national entry-level induction for all who join health and social care."* (From the Health and social care review: leadership for a collaborative and inclusive future report, 2022)

Importance of effective leadership

Effective leadership and oversight from a Trust board is vital to ensure safe and personalised care. This includes taking ownership of the safety of their services, and making sure that their

teams have the relevant skills to provide high quality, compassionate care for mothers and babies.

The interim Ockenden report highlighted the importance of strengthening leadership and oversight for maternity, addressing toxic workplace behaviour and cultures, and fostering collaborative approaches. The leadership team is strongest when the service level manager, midwifery and obstetric leaders are all in place and work well together.

Concerns on leadership from CQC:

CQC reports continue to state issues with governance and lack of oversight from boards, including challenges in identifying issues and packages of support at service delivery level. In their 2021 programme of focussed inspections, some of the maternity services the CQC visited did not have all leaders needed in post, or they were held by interim postholders. The lack of stable leadership may prevent long-term collaboration and leadership development.

There needs to be ongoing commitment to improve leadership, at both a national and board level, as well as clarity over the role of Integrated Care Systems and their Local Maternity and Neonatal Systems in the oversight of the safety and quality of services.

Importance of training

Evidence suggests that regular multiprofessional training in maternity can improve patient outcomes. Sands and Tommy's Joint Policy Unit published our first progress report in May 2023, bringing together data from different sources for the first time to show the extent of pregnancy loss and baby death across the UK. In a section on training, findings included in the report were:

- While regular multiprofessional training did take place in services visited by the CQC, the impact of the training was not always consistent or evaluated.
- Particularly important is training centred on themes emerging from incidents – one service introduced unannounced short training sessions to respond to specific scenarios. One example was a woman giving birth to twins in a toilet.
- Some services lacked training or training was not attended by some staff members, including consultants and anaesthetists, leading to concerns that some staff did not have the required skills and knowledge to perform certain tasks. Some services had switched to virtual training or paused training during the pandemic.

The MBRRACE confidential enquiries into Black and Asian baby deaths identified a number of key issues along the care pathway, where the quality of care provision differed between the Black, Asian and White groups. These highlight the need for ensuring all women receive personalised care which is sensitive to their individual circumstances. The reports recommended developing training and resources for all maternity and neonatal staff, so they can provide culturally and religiously sensitive care for all mothers and babies.

Safe staffing levels and training

Our progress report also analysed the impact of insufficient staffing on training. Some of the findings were:

- Insufficient staffing not only has an impact on the number of healthcare professionals available to deliver care, but also the availability of staff to participate in training which affects both their personal development and retention, as well as patient safety. The impact of cancellation and postponement of training on the quality and safety of maternity services was highlighted in the Maternity and Baby Loss APPG's report of staffing shortages. In its Mind the Gap report, the charity Baby Lifeline has highlighted significant gaps in maternity training, with fewer than a quarter of services in England providing all the training elements outlined in NHS England'smu Saving Babies' Lives Care Bundle. The NHS 2022 staff survey in England found that less than half of midwives (46.9%) felt supported to develop their potential, compared to 54.7% of all staff.
- Total staffing ratios ignore individuals' level of experience and the skills mix within staff groups. Within staffing groups, it is important to have an appropriate mix in levels of experience in order to deliver high quality care, as well as provide ongoing professional development training for junior staff.
- Neonatal services faced particular recruitment challenges due to the lack of exposure to neonatal specialities – there is a lack of opportunities for most pre-registration nurses to access neonatal-specific placements and limited exposure to neonatology for midwives in training. The lack of clear career structure or remuneration for neonatal specialist training may make neonatology a less attractive option for newly qualified nurses.

Policy area - Culture of safety/whistleblowing

Recommendation 1: ***"Culture of safety: Every organisation involved in providing NHS healthcare, should actively foster a culture of safety and learning, in which all staff feel safe to raise concerns. Action 1.1: Boards should ensure that progress in creating and maintaining a safe learning culture is measured, monitored and published on a regular basis. Action 1.2: System regulators should regard departure from good practice, as identified in this report, as relevant to whether an organisation is safe and well-led."*** **(From the Freedom to Speak Up Review, 2015)**

Reports have consistently identified safety culture as an issue in maternity and neonatal services, with the Ockenden Report promoting collaboration between maternity and neonatal teams, to improve care and outcomes.

Maternity Incentive Scheme:

The Maternity Incentive Scheme was introduced to support the delivery of safer maternity care. Previous research has found:

- An interim evaluation in 2020 found that in the second year of the Scheme, 117 out of 130 trusts (90%) certified as having achieved all ten safety actions, a significant uplift on year one. Trusts reported an improvement in safety culture through the scheme, particularly as a result of different teams working together towards the objectives, enhancing multiprofessional working. However, it is not clear what the impact of these initiatives are on maternity outcomes more widely, whether the scheme is supporting improvements in safety and how this is being evaluated.
- Our recent report on board oversight (see above) found that there is a need to review the extent to which the Maternity Incentive Scheme in its current form incentivises transparent reporting of performance issues so that they can be addressed in a timely way. There is a risk that the boards and services focus on demonstrating compliance with the scheme rather than supporting the improvements in safety. Without a system which incentivises transparent reporting and provides support for areas of need, Trusts may prioritise financial certainty and reputation management over a culture of learning and improvement.

Wider concerns around safety of services:

- Reports show difficulty for staff to escalate concerns, with HSIB finding 'rigid processes' for escalation in some units which disempower staff from seeking support. They found poor staff handover in some units and a lack of awareness of guidelines. Strengthening relationships between teams would improve communication and make staff more comfortable to escalate concerns.
- There is an existing culture of blame due to the nature of litigation on serious patient safety incidents. As the 2021 Health and Social Care Committee report on maternity services stated, awarding compensation through proving clinical negligence has created a fear of litigation which stifles learning, making the system less safe for parents. As a result, parents are too often left without 'the appropriate, timely and compassionate support they deserve'. As the report suggested, the current clinical negligence process should be examined further to understand the implications it is having on staff and families, with alternative processes explored.
- The CQC 2022 maternity survey shows that, at a national level, people's experiences of care have deteriorated. In 2022 only 63% of women and birthing people said they were 'always' able to get a member of staff to help them when they needed attention during labour and birth, compared to 72% in 2019. 77% of women and birthing people said that if they raised a concern during labour and birth, they felt it was taken seriously - down from 81% in 2017.

- The CQC maternity survey does not include the voices of bereaved parents, but Sands bereaved parents' experiences of care report found that 34% of parents who lost their baby did not have confidence in the staff caring for them. Almost half felt more could have been done for them and their baby.
- The Ockenden report found that the Shrewsbury & Telford Hospitals Trust board did not have oversight, or a full understanding of issues and concerns within the maternity service. This led to a lack of strategic direction, a failure to make effective changes and an absence of accountable implementation plans.

Steps should also be taken to ensure that all maternity safety improvement schemes include a focus on tackling inequalities, with action, progress and impact monitored.

Towards a 'Just Culture' for safer maternity care

A 'Just Culture' supports safe care and is an important element of good bereavement care, by acknowledging that something has gone wrong and committing to understanding why.

Sands have found that the word parents value hearing is 'sorry'. Currently, professionals may feel awkward saying sorry because it could be interpreted as an admission of liability. However, in UK law (except in Northern Ireland), saying sorry does not mean that you are admitting blame, as explained in this resource created by Sands. Some fear being unfairly blamed, while others focus on issues in the health system which leads them to believe blaming individuals is unfair.

We need a culture that is open and candid, to share what has gone wrong and what needs to improve. The end goal is not accountability or a learning culture, but safer, personalised and equitable care. Regulation, therefore, needs to support an approach which enables improvement rather than apportions blame.

Jan 2024