Witness Name: [Harmer]
Statement No.: [XXXX]
Exhibits: [XXXX]
Dated: [XXXX]

THIRLWALL INQUIRY

WITNESS STATEMENT OF Clea Harmer, Chief Executive of Sands

I, Clea Harmer, Chief Executive of Sands will say as follows: -

1. Sands exists to reduce the number of babies dying and to support anyone affected by the death of a baby, before, during or shortly after birth, whenever this happened and for as long as they need support.

2. Babies are dying every day. Currently in the UK, 13 families a day suffer the heartbreak of losing their baby before, during or shortly after birth. That is around 4,500 babies a year.

3. Currently, far too many babies die without scientists, doctors, midwives, or their own parents understanding why. That's why Sands believes research is vital in improving our understanding of how to save babies' lives and using that evidence to drive changes in maternity and neonatal policy and practice.

4. For more than 40 years, Sands has been here for anyone affected by pregnancy and baby loss to offer understanding and comfort through our Freephone helpline, mobile app, online community, and resources, and also locally through a UK-wide network of around 100 regional support groups.

5. Sands works in partnership with health care professionals, trusts and health boards and offers a range of training programmes and bereavement care resources to ensure that every bereaved parent and family receives the best possible care wherever they are in the UK.

6. The charity also raises awareness of baby loss and works with governments, key influencers and other stakeholders to make reducing the number of babies dying a priority nationally and locally.

7. Sands has support groups in the following areas of the UK
    a) England 39

    b) NI 10

    c) Scotland 13

    d) Wales 5

8. Sands also has 40 Sands United Football clubs across England, Wales and Northern Ireland, providing sports-based peer support, currently for men only.

9. Sands leads the National Bereavement Care Pathway (NBCP) project, which is being rolled out to NHS Trusts across England. The project aims to improve the quality and consistency of bereavement care received by parents after pregnancy loss or the death of a baby. The pathway is based around nine core standards and addresses five experiences of pregnancy loss and the death of a baby, one of which is neonatal death Exhibit CH/0a [**INQ0012943**] and Exhibit CH/0b [**INQ0012944**]. As well as offering guidance, the National Bereavement Care Pathway offers practice support workshops, and access to training and resources. We do not, however, observe practice in unit and encourage hospitals to self-assess the bereavement services they provide. We have offered a bereavement care consultancy service in two Trusts, where we spoke to stakeholders about local service provision and then provided feedback on the level of care provided against the National Bereavement Care Pathway standards.

10. The Countess of Chester Hospital was not signed up to the National Bereavement Care Pathway until January 2024 and was one of the last 3 of 128 NHS Trusts in England to sign up. Prior to that, Sands had regular contact with the hospital about the pathway. They sent in an expression of interest quite early on after the programme was opened up in 2019/20 and attended several National Bereavement Care Pathway workshops, for example in July 2019 and September 2021.

11. Sands has not been commissioned to provide any bereavement care training workshops in the Trust, though NHS staff may have accessed some of our open-access training webinars.

Support Services

12. Sands has the following support services Exhibit CH/1a [**INQ0012947**] available for bereaved families or families of premature or sick babies:

   a) Sands Helpline – a free helpline 5 days a week to support anyone affected by the death of a baby at any gestation and any type of loss.

   b) Sands Support chat – webchat provision for anyone wishing to access counselling support via webchat, used proportionally more by men, but open to all.

   c) Sands Memory-making resources – Memory boxes and resources to facilitate conversations and opportunities to make and keep memories e.g. hand and footprint kits, baby details books. Muslim Care and Burial boxes also available containing resources for care of a baby prior to burial including baby shroud.

   d) Sands Bereavement Support Book – which is also available in an easy read version and has been translated into 11 further languages Exhibit CH/1b [**INQ0012948**].

   e) Local support groups around the UK, from Shetland to Guernsey run by trained Befriender volunteers providing peer support.

   f) Online /Support Meetings – various regular online support meetings including general support, men's support, Black and Black British support, South Asian support.

   g) Sands Online Communities - various online groups via Facebook and a Sands hosted community providing peer to peer support which is moderated by bereavement team staff throughout the week.

   h) Sands United Football Clubs – a network of clubs around the UK, currently for men to play football and receive peer support.

i) Support for Black & Black British bereaved families and for South Asian bereaved families – specific support and community-building acknowledging the barriers in access and health care for these families, facilitated by specialist staff.

13. Any parent who contacts Sands will be signposted to external provision if appropriate. Whilst we aim to provide support within Sands via a wide variety of channels and specialisms, we acknowledge that bereaved parents have complex needs, that bereavement does not happen in a vacuum, and that additional support may be needed. We refer to mental health provision, counselling services and charities with specific expertise around finance, legal advice and other relevant expertise.

14. Sands has clear safeguarding processes with four tiers of escalation as necessary. All staff are required to undertake safeguarding training and familiarise themselves with the safeguarding policy, which is regularly reviewed. It includes information to help identify signs of abuse. Staff are also made aware of Sands' Whistleblowing Policy, which states the organisation's expectations for anyone working to represent our ethical values. It explains the lead contact and the different ways in which to raise concerns about existing practices or peers, especially for colleagues working in teams where there is contact with vulnerable people. The Helpline staff also have a safeguarding practice guidance document to help identify risk and occasions when breaching confidentiality may be necessary. There is also a safeguarding log with guidance on assessing risk. The safeguarding log is kept securely (with restricted access) and if a Helpline interaction is identified as pointing to a safeguarding risk, staff must inform a manager who will debrief with them. There is always a designated manager responsible for safeguarding whenever the Helpline channels are open. They complete the log and alert the rest of the team in shift handover notes, so that if the person contacts the Helpline again then can be supported effectively. Any agreed actions are carried out. There is also an anonymised record of safeguarding interaction by type and severity. This data is reported to the Board of Trustees and can be used to see trends and enhance our service offer. For example, the number of callers who disclose domestic abuse has led to planning for specialist support.

15. The Bereavement Support Services webpage states all calls are confidential, but confidentiality may be breached if a person's safety is at risk. All staff are trained in both safeguarding and confidentiality. It is a requirement that all Bereavement Support Services staff work in a private space to maintain confidentiality, and they know that

information about calls, support emails and online interactions must not be disclosed to third parties. However, they also understand that breaches of confidentiality may be necessary when there is risk to a person's safety. The safeguarding practice guidance includes a flow chart on when to break confidentiality. If a Bereavement Services Support Officer believes that a breach of confidentiality may be needed, they escalate to a Bereavement Support Lead or Head of Bereavement Support Services rather than making the decision themselves. Staff only communicate with Helpline users through the channel the user has chosen, unless they specifically ask for another channel to be used (e.g. emailing to ask for a telephone call). They are also alert to possible lack of privacy for Helpline users and will not initiate a call without an explicit request and permission. Staff can disclose whether or not they are bereaved parents themselves if asked directly, if they believe it would be helpful for the caller to know, and if they wish to do so, but they also know that they have a right to privacy and do not have to disclose.

16. Parents contacting Sands for support or information sometimes raise concerns about the care they received. We have created a short resource to help parents raise issues or concerns, available on our website Exhibit CH/3 [**INQ0012949**]. This resource is also used by our Bereavement Support Services team for use in conversations with bereaved parents.

17. Sands does not directly observe the provision of care. However, Sands staff come into contact with NHS staff at events, workshops or training webinars. Sometimes those staff will disclose concerns to us, for example about poor culture, bullying, understaffing or unsafe practice. Sands has worked to develop an internal process for responding to instances where this has happened and has sought legal advice on this process.

18. The process aims to help Sands staff to:

    a) Hold a safe space so that if NHS staff raise concerns with us, they feel heard.

    b) Explain the support that Sands can offer to NHS staff as well as the limitations of that support.

    c) Actively encourage the NHS staff member to report any concerns they may have about poor and/or dangerous practice themselves.

d) Provide information about local and national reporting mechanisms and the safeguards available to staff, including anonymous reporting.

e) If the issue raised is very serious and represents an immediate danger, follow Sands safeguarding policy to explore whether Sands should breach confidentiality and report the incident to the Care Quality Commission (CQC - England), Health Improvement Scotland (HIS), Health Improvement Wales or Regulation and Quality Improvement Authority (RQIA) (Northern Ireland).

f) Inform staff that they should not attempt to investigate or resolve the issue themselves.

g) Understand the support available to Sands staff to look after themselves and seek help when they need to.

Working collaboratively with the NHS and medical professionals

19. The majority of Sands referrals are self-referrals by bereaved parents and families themselves. Referrals may also come from healthcare professionals, other charities, and statutory organisations. These will come by phone, email, social media messaging and Sands Griefchat.

20. Sands Hospital Liaison Volunteers provide a link between hospitals, Sands local support groups and Sands national services. These specially trained, local volunteers signpost NHS staff working within the hospital to Sands resources, support services training and bereavement care guidance for NHS staff. Thus they enable parents and families to access support after pregnancy loss and baby death. These volunteers make NHS staff working in hospitals aware of the services we offer as a charity so that they can pass this information on to parents and families who may wish to take up our services.

21. Our long-term aim is to ensure that every hospital in the UK has access to a Hospital Liaison Volunteer. We currently have 114 Hospital Liaison Volunteers operating throughout England and Scotland. We have a Hospital Liaison Volunteer in place at the Countess of Chester Hospital who has been in place since September 2023.

22. Since 2012, when the majority of contact was by phone, the development of new channels for support and statistical data gathering have increased. Many more people now interact on social media than by phone, but the numbers calling remain significant.
23. Our monthly reach across all Bereavement Support provision now hovers around 5,000. This includes Facebook - general and specific groups and pages, Sands Online Community, phone, email, our webchat service Griefchat, Memory boxes and bereavement resources. Call data is listed below.

Contacts to BSS team by parents, siblings and health care professionals (HCP)

		20/21	21/22	22/23	23/24	Totals
Contacts	**Parents**	3,945	3,668	2,830	1,895	**12,338**
Contacts	**Siblings**	114	140	194	96	**544**
Contacts	**HCP**	546	412	431	309	**1,698**
Contacts	**GriefChat Chats**	831	958	1681	1412	**4882**
Users	**OC Users**	7176	8417	9343	10235	**35171**
Users	**FB Members**	1125	3053	4701	5386	**14265**
		13,737	**16,648**	**19,180**	**19,333**	**68,898**

24. In addition to parents, siblings and HCPs we provide information to a wide range of contacts including grandparents, wider family, funeral directors, solicitors, friends, teachers, probation officers, police, and others impacted by pregnancy loss and baby death. These numbers therefore are only a proportion of the support we provide.

Working with policymakers

25. Sands has raised concerns about maternity and neonatal care with policy makers, including initiatives to improve safety to reduce rates of stillbirths and neonatal deaths. Our concerns are best summarised in the progress report of the Sands and Tommy's Joint Policy Unit Exhibit CH/6a [**INQ0012950**] and Exhibit CH/6b [**INQ0012951**].

26. In 2022, Sands and Tommy's came together to form a Joint Policy Unit 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. Through this unit we have raised concerns with policymakers more widely about the safety of maternity and neonatal services (rather than safeguarding specifically). In May 2023, the Joint Policy Unit published its first progress report that brought together data from different sources for the first time to show the extent of pregnancy loss and baby death across the UK. The report outlined recent trends and evidence, as well as gaps in our understanding, and it set out key areas where we though action is required to reduce rates of miscarriage, stillbirth, preterm birth and neonatal death, as well as to address inequalities in these outcomes. The report is organised under the following themes:

a) Not enough progress has been made to reduce rates of pregnancy loss across the UK, and there is a risk of going backwards

b) Factors associated with higher risk for pregnancy loss and baby deaths are complex and changing

c) Meaningful action is needed to address stark and persistent inequalities in ethnicity and deprivation

d) Systems issues in maternity and neonatal services need to be addressed

e) Lessons are still not being learnt when babies die

f) Too often nationally agreed standards of care are not being followed which is contributing to avoidable deaths

g) Research and evaluation are vital for improving outcomes in the future.

27. The report was shared with politicians, the Department for Health and Social Care, NHS England and Royal Colleges amongst others. It was launched at an event at Westminster which the Health Minister attended.

28. Sands also provides the secretariat of the All Party Parliamentary Group on Baby Loss, where issues surrounding maternity and neonatal safety have been discussed. We supported a joint inquiry with the All Party Parliamentary Group on Maternity which looked at safe staffing in maternity services. In addition, when we surveyed healthcare professionals caring for families after the death of a baby we found that

less than half of NHS trusts and boards across the UK make training available, and only 12% of healthcare professionals were given time during working hours to attend.

29. In December Sands published our Listening Project Report Exhibit CH/7 [**INQ0012952**] highlighting the barriers, biases and poor care that may be contributing to inequalities in baby deaths across the UK. This report was published on the same day as the MBRRACE-UK confidential enquiries into Black and Asian baby deaths which were based on a review of the mother and baby's medical notes. To complement this, the Listening Project report focused on the experiences of 56 Black and Asian bereaved parents, who we spoke to during 2023 to learn about the maternity, postnatal and neonatal care they had experienced.

30. Some of the families we spoke to believed that not being listened to and not having their concerns taken seriously led to important warning signs going unnoticed, investigations not being carried out and opportunities to save babies' lives being missed. Half of the parents who took part believed that they had received worse care or been treated differently by healthcare staff because of their ethnicity. Parents described a range of safety issues that fell within four key areas of care:
    a) Being listened to and heard

    b) Personalised, joined-up care

    c) Communication about safety and risk

    d) Safety and learning

31. Sands is committed to identifying policy changes that will reduce inequalities in pregnancy and baby loss, and the Sands and Tommy's Joint Policy Unit is currently undertaking a programme of work focussed on addressing inequalities throughout pregnancy, birth and the neonatal period. This includes work to map out the multiple potential drivers of inequality, with a view to building consensus on key policy changes needed to address them. Following the report publication, we are asking Governments across the UK to:

    a) Set out long-term, funded plans aimed at eliminating inequalities in pregnancy loss and baby deaths.

b) Ensure that maternity services have the staff capacity, skills and resources required to assess and care for women and birthing people effectively, so that the risk factors affecting each individual are recognised and their impact reduced.

c) Initiate and fund a research programme to inform the development of effective interventions to address health inequalities and save babies' lives.

d) Take steps to ensure that all maternity safety improvement schemes include a focus on tackling inequalities, with action, progress and impact monitored.

32. We are also encouraging our supporters to contact their elected representatives about this and ask them to raise it with the relevant minister. A number of questions have been raised in parliaments across the UK and in England the Health and Social Care Secretary announced £50 million for research to tackle maternity disparities, as one of the government's priorities for women's health in 2024.

33. Sands and Tommy's co-lead the Maternity Consortium, which forms part of the government's Voluntary Community and Social Enterprise Health and Wellbeing Alliance. The Alliance is a partnership between sector representatives and the health and care system, and it was established to enable the voluntary sector to share its expertise at a national level with the aim of improving services for all communities.

34. Through the Maternity Consortium we are undertaking a project to support the implementation of Local Maternity and Neonatal Systems' Equity and Equality plans. The aim of this project is to work across the maternity and neonatal system at national, regional and local level to share knowledge, existing resources, and good practice which support the implementation of equity and equality plans.

35. The Maternity Consortium has previously supported a project – led by the charity Bliss – to work with healthcare professionals and families to develop a resource for Local Maternity Systems and Neonatal Operational Delivery Networks to support education and improve communication skills within the neonatal unit.

36. The Maternity Consortium has also undertaken a project focussed on engaging with diverse communities to improve access to appropriate services for those at risk of poorer maternity outcomes.

37. There is widespread recognition that reports and reviews into the safety of maternity and neonatal services across the UK consistently identify similar themes, and that these themes keep recurring despite steps to implement recommendations from past reports.

38. The report into East Kent maternity services made clear that the failings identified were not one-off or isolated incidents. It is vital that lessons are learned from these numerous reports and reviews at a national level and that they inform our policy approaches to improving maternity and neonatal services.

39. Sands and Tommy's Joint Policy Unit has undertaken work to identify key recurring themes from previous reviews and reports into maternity and neonatal services – focussing on those areas most relevant to the Unit's core aims of saving babies' lives and reducing inequalities in loss. The common themes identified are as follows:

    a) Staffing levels and training: Staffing levels need to be sufficient to ensure safe care. Workforce plans must be owned by the board with clear mitigation/escalation policies in place when staffing is unsafe. Staff must be suitably qualified with senior staff present on labour wards. All staff must have access to the training that is required for them to carry their roles safely and effectively. To support teamworking, training should be multi-professional; support working together with a shared purpose; and include a focus on situational awareness and human factors.

    b) Culture of safety within organisations: Staff must be able to escalate concerns about clinical care whenever necessary, with clear protocols in place to support this. Staff must be able to report safety concerns without fear of reprisal or repercussions. Organisations must review their approach to reputation management and ensure an open learning culture from board to ward level.

    c) Organisational leadership: Safe care must be a shared goal throughout organisations. Boards must take effective ownership of the safety of maternity services with strong oversight of quality and performance of services. Clear arrangements should be in place for sharing patient experience at board level.

d) Personalisation of care and choice: All women and birthing people should be able to make informed decisions about their care. This includes decisions about mode and place of birth – based on full, impartial information about the safety risks associated with all birth options.

e) Reducing inequities: Initiatives need to be focussed on improving care for those at increased risk of worse outcomes to reduce rates of miscarriage, stillbirth, neonatal death and preterm birth. This includes accurately recording data on ethnicity and using it to respond to risk factors. It also involves working with women and birthing people from minoritised ethnic backgrounds, and other disadvantaged communities, to tailor care and improve outcomes.

f) Data collection and use: Data collection must help identify variation in outcomes between maternity units, and among different patient groups (for example among women from Black and minority ethnic groups). Steps must be taken to understand the causes of variation and to inform improvements. Better data collection needs to be supported by improving access to digital maternity records.

g) Learning from reviews and investigations: There should be a standardised, consistent approach to reviews and investigations of serious incidents, with families involved in a compassionate manner. Systems must be in place to support the sharing of learning locally, regionally, and nationally – with clear actions implemented to address concerns raised. There must be adequate resources for comprehensive reviews and investigations to take place.

h) Engaging with service users: Maternity and neonatal services must actively engage with, learn from, and listen to the needs of women.

i) Delivering care in line with nationally agreed standards: Reports have consistently highlighted the need to provide timely and responsive care in line with national guidelines.

40. As highlighted earlier, the Joint Policy Unit analysis of a range of recent reviews and investigations of maternity and neonatal services identified the lack of a culture of safety within organisations as a key recurring issue. Staff must be able to escalate concerns about clinical care whenever necessary, with clear protocols in place to support this. It is clear from numerous previous investigations that there continue to

be barriers to doing this and that too often reputation management is prioritised over a culture of learning and improvement.

41. Across the UK, not enough progress is being made on reducing rates of pregnancy and baby loss, and there are stark and persistent inequalities by ethnicity and deprivation.

42. Recent and ongoing reviews have highlighted significant issues with the safety of neonatal and maternity services. The Government have made various commitments to act because of these reviews but despite an increased policy focus on safety, we have not seen the fundamental change required to ensure safe, equitable care for all. The current maternity safety ambitions in England are also due to come to an end in 2025.

43. Not only is there a strong moral case to provide safe and equitable neonatal and maternity care, but there is also a compelling financial case. The cost of harm from clinical negligence caused by NHS maternity services was £8.2 billion in 2021-22, 60% of the total clinical negligence bill in the NHS and more than double what the health service spends on maternity care.

44. Shifting spend to neonatal and maternity care is key to prevention, and addressing issues early on will lead to more efficient use of the public purse by reducing costlier specialist interventions further down the line, ultimately reducing demand on the NHS, social services and education.

45. Data published by MBRRACE-UK, showed an overall increase in the rates of babies dying before or shortly after birth in 2021. It also highlighted marked increases in inequality by ethnicity and deprivation, with the highest neonatal death rates being for babies of Pakistani and Black African ethnicity from the most deprived areas, at over 3 per 1,000 live births.

46. The recent announcement of £50 million for research to tackle maternity disparities is welcome, but the success of this fund will be in how it is implemented. We would like to see funding allocated to research looking at effective interventions to reduce maternity disparities so we know what works and can be implemented to prevent baby deaths.

47. The Government must focus on making progress in these areas. While there is a wide range of activity underway, there remains a long way to go to ensure lessons from previous reviews and reports are leading to improvements in the safety and equity of services. The Government must ensure that policy initiatives are properly evaluated to understand the impact they are having.

48. The Joint Policy Unit's report looking at NHS Board oversight of maternity and neonatal services Exhibit CH/10 [**INQ0012945**] reviewed publicly available board papers from seven NHS Trusts in England to analyse board oversight of maternity and neonatal services. To select a representative sample of Trusts we used Trust-level data from Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries across the UK (MBRRACE-UK) on stillbirth and neonatal mortality rates, excluding congenital abnormalities. The Countess of Chester NHS Foundation Trust was not one of the Trusts reviewed. Although we used perinatal mortality data to select the sample, our review focused on whether board reporting and discussions were robust and candid, rather than on individual Trust's performance. We would be happy to share the individual analysis of each Trust with the inquiry.

49. The review focused on three areas:
    a) The quality and content of reports and data presented to boards

    b) Whether there was a robust and candid review process at board level

    c) What actions (if any) were agreed to address concerns.

50. This work was not intended to single out particular NHS Trusts. Instead, we wanted to find common themes between Trusts to inform policy recommendations. Our findings across these three areas raised questions about boards' ability to have a full understanding of the performance of maternity and neonatal units under their direction under the current system:

    a) Quality and content of reports and data presented to boards
        I. Despite the list of minimum data measures for Trust board overview set out in NHS England's Revised Perinatal Surveillance model, the data included in board papers varied widely. There were also a wide range of additional metrics reported by many Trusts, without explanation.

II. Variation means that 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.

III. Board reports had large quantities of hard-to-digest information and didn't appear designed to support informed decision making. Five out of the seven Trusts reviewed had reports which included charts or diagrams which were not legible.

IV. Data and intelligence are spread across multiple reports. This makes it hard for board members to have oversight of what is going on in maternity and neonatal services.

V. Reports included little to no additional analysis to draw attention to metrics or trends which might suggest the services are off-track or declining.

VI. Few board papers included external data, such as from the National Neonatal Audit Programme (NNAP), Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries across the UK (MBRRACE-UK), or the Office for National Statistics (ONS), to contextualise local performance against national trends and targets.

b) <u>Robust and candid review process at board level</u>

I. The minutes of public board meetings show that discussion of the papers related to maternity and neonatal services was often limited. Papers are often noted for approval without discussion or refer to more detailed discussions which have happened elsewhere.

II. Trust boards review information from across the Trust which makes focusing on particular services challenging. Across the meetings reviewed, agendas allocated between 5–30 minutes to discuss maternity services. Often, although not always, meeting time was spent presenting messages rather than discussing the implications.

III. Detailed discussions happen elsewhere and sub-committees, such as Safety and Quality Committees, appeared to discuss service performance in more detail. However, reports to the board often referred broadly to "actions" or "themes" emerging from discussions but with insufficient insight to allow effective scrutiny by the board.

IV. Most Trusts reviewed had only limited discussion of the maternity and neonatal reports. There were some examples of more effective engagement. Board members in one of the Trusts appeared particularly engaged, citing recent national reports or statistics and asking how the Trust performed in relation to those concerns

c) <u>Actions to address concerns</u>

I. Mitigating actions were not decided by board members. While some board members did ask questions or for further information, no actions were decided by board members. More often the reports included mitigating actions which had been decided by the services themselves, and boards did not offer much scrutiny as to whether they were sufficient or to request updates on previous actions.

II. Questions or clarifications are rarely revisited. When board members did ask for clarifications, updates were rarely followed up on. The threshold to adding an item to an action log appears to be high as very few comments result in a new action. This means that legitimate questions are not publicly responded to.

51. Our review has highlighted the need for:

a) Further guidance on the minimum metrics to be submitted to boards, including any new measures identified by the Maternity and Neonatal Outcomes Group to provide an early warning of service quality and safety declining.

b) Better ward-to-board communication to contextualise data, including more analysis from Clinical Service Leaders to interpret metrics, and more board member engagement with wards and staff.

c) Reports which reflect on and contextualise metrics and trends over a longer time frame in addition to regular service monitoring dashboards.

d) A review of current systems and processes in each Trust and whether they allow boards to have meaningful oversight over the quality and safety of services.

e) Transparent reporting of issues discussed outside of public board meetings, such as at sub-committee level.

f) A review of whether the maternity incentive scheme prioritises financial certainty and reputation management over a culture of learning and improvement.

g) Clarity over the role of Local Maternity and Neonatal Systems in oversight of quality and safety and the implications for Trust boards' responsibilities.

52. Recent reviews and investigations of maternity and neonatal services have identified the lack of a culture of safety within organisations as a key recurring problem. Staff working within services must feel more able to escalate concerns about care whenever necessary, without fear of repercussions. We fear that too often reputation management is prioritised over a culture of learning and improvement. We must focus on systems change, including the support NHS Trusts need to embed and sustain improvements to move away from a culture of denial and blame, and instead to incentivise candour, support improvements, and systematically revisit recommendations to ensure sustained change.

53. Without a just culture of openness and without 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.

54. An open learning culture across neonatal and 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.

55. Listening to the voices and experiences of bereaved parents will help to drive a change in culture and must be at the heart of all policies developed to save babies lives and improve future care. In June 2023, Sands launched an online survey asking bereaved parents about their experiences of all aspects of their care Exhibit CH/11 [**INQ0012946**]. We were keen to identify gaps and inequalities in maternity care to

drive improvements across the UK. We promoted the survey through social media and other communications channels and received almost 2,000 responses. We were able to analyse 1,699 of these. The key findings from the report were:

a) The experiences of parents whose baby spent time in a Neonatal Intensive Care Unit (NICU), or a Specialist Care Baby Unit (SCBU) were significantly better compared to other parts of the care pathway and had improved over time. 75% felt they were treated with respect, 79% agreed that they had all the necessary tests and monitoring done, and 85% agreed that all the equipment and facilities were available. However, 26% felt that their choices and opinions were not taken seriously.

b) Parents' experiences of bereavement care have improved over time, with 88% saying they were able to make memories of their baby in the last three years compared to 74% before this.

c) The proportion of parents who were told about reviews and investigations into their care has more than doubled, and more parents were offered the opportunity to share their questions and concerns with the team reviewing the quality of their care.

d) Among people who lost their baby more recently, 34% did not have confidence in the staff caring for them; almost half felt more could have been done for them and their baby.

e) The average time it takes for parents to receive their post-mortem results has significantly worsened. Not only has it doubled over the two time periods, but the proportion of parents waiting six months or more has trebled.

Statement of Truth

56. I believe that the facts stated in this witness statement are true. I understand that proceedings may be brought against anyone who makes, or causes to be made, a false statement in a document verified by a statement of truth without an honest belief of its truth.

Signed: ________ **Personal Data** ________________________

Dated: ____________19th March 2024______________________