Witness Name: Dr Ngozi Edi-Osagie
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THIRLWALL INQUIRY

WITNESS STATEMENT OF DR NGOZI EDI-OSAGIE

I, Dr Ngozi Edi-Osagie, will say as follows: -

1. I provide this witness statement in my capacity as National Clinical Director for Neonatal Care.

2. I would like to start by emphasising that most families do not expect to have a baby who requires neonatal care, and therefore alongside providing specialist care, neonatal services should also provide support for families at time when they are perhaps at their most vulnerable. The expectation of compassionate care makes the events that have led to this inquiry particularly distressing, and I would like to extend my deepest sympathy to the families affected.

3. This statement seeks to address the issues set out in the Rule 9 request sent to me by the Inquiry on 15 January 2025. I have sought to respond to the Inquiry's questions as best as I am able. This statement was drafted on my behalf by the external solicitors acting for NHS England in respect of the Inquiry, with my oversight and input. It is the product of drafting after communications between those external solicitors and me, in writing and by video conference.

Background and career history

4. Since June 2002, I have been a Consultant Neonatologist at Saint Mary's Hospital which is part of Manchester University NHS Foundation Trust ("MFT"). The neonatal unit at Saint Mary's Hospital is one of the largest and busiest neonatal intensive care units in England. I undertook my paediatric and neonatal training at various hospitals in the Northwest Region and London. For nine years I was the lead neonatologist at MFT initially as Clinical Lead, then Clinical Director, and finally Clinical Head of Division. I was also one of the Group Associate Medical Directors for Manchester University NHS Foundation Trust for 8 years. From 2016 – 2019 I was one of two clinical leads for the development of a single

hospital service across the city of Manchester which merged three trusts and 10 hospitals. I exhibit a copy of my CV at **NEO/1, INQ0108886.**

5. I am on the specialist register of the General Medical Council, I am a Fellow of the Royal College of Paediatrics and Child Health ("RCPCH"), and a member of the British Association of Perinatal Medicine ("BAPM"), British Medical Association ("BMA"), Faculty of Medical Leadership and Management and the Health and Care Women Leaders Network NHS Confederation. I am also president of the section of Paediatrics, Manchester Medical Society.

6. I have been the chair of the NHS England Neonatal Clinical Reference Group since 2020. From 2022-2024 I was the National Specialty Advisor for Neonatal Care at NHS England. Since 1 February 2024 I have been the National Clinical Director for Neonatal Care at NHS England. I was appointed through a competitive process for these roles, and I describe the Director role in more detail later in this statement.

Key terms and definitions

7. The following definitions are not intended to be a comprehensive explanation, but merely to assist the Inquiry with understanding of some of the terms used in this witness statement:

    a. **Operational Delivery Networks (ODNs)** are a managed clinical network of neonatal providers focused on coordinating patient pathways between neonatal units over a geographical footprint. This is to ensure access to specialist resources and expertise are available in each network to minimise necessary travel for parents and their babies when this expertise is required. There are 10 Neonatal ODNs in England.

    b. **Neonatal Intensive Care Units (NICUs):** provide intensive care (highest level of care) for the sickest, smallest and most immature babies across a clinical network. They also provide high dependency (medium level of care), special care (lower level of care) and transitional care (lowest level of care provided alongside the mother) for their local population. They work closely with their local maternity teams and fetal medicine services. There are 43 NICUs in England.

    c. **Local Neonatal Units (LNUs):** provide short-term intensive care (up to 2 days); high dependency care, special care and transitional care for their local populations. LNUs would not be expected to provide ongoing or complex intensive care beyond

initial stabilisation to babies less than 27+0 weeks gestation or birth weight <800g. There are 73 LNUs in England.

d. **Special Care Units (SCUs):** provide special care and transitional care for babies for their local populations who do not need intensive care. SCUs would not be expected to provide ongoing care beyond stabilisation to babies less than 32 weeks gestation or birth weight <1000g. There are 39 SCUs in England.

Abbreviations

NCD	National Clinical Director
RCPCH	Royal College of Paediatrics and Child Health
BMA	British Medical Association
CRG	Clinical Reference Group
NSA	National Specialty Advisor
ODN	Operational Delivery Networks
NICU	Neonatal Intensive Care Unit
LNU	Local Neonatal Unit
SCU	Special Care Unit
NICE	National Institute of Health and Care Excellence
BAPM	British Association of Perinatal Medicine
HQIP	Health Quality Improvement Partnership
NCMD	National Child Mortality Database
NIHR	National Institute for Health and Care Research
NNAP	Neonatal Audit Programme
BLISS	A charity for babies born premature or sick
NNA	Neonatal Nurses Association
SSQD	Specialised Service Quality Dashboard
MBRRACE	Mothers and Babies: Reducing Risk through Audits and Confidential Enquiries
LMNS	Local Maternity and Neonatal System
NDB	Neonatal Delivery Board
NCCR	Neonatal Critical Care Review
MNSI	Maternity and Newborn Safety Investigations
GMC	General Medical Council
NMC	Nursing and Midwifery Council

PQSM	Perinatal Quality Surveillance Model
PQOM	Perinatal Quality Oversight Model
NMPA	National Maternity and Perinatal Audit
MOSS	Maternity Outcomes Signal System

National Clinical Director for Neonatology

8. As set out at paragraph 1003 in the First Witness Statement of Professor Sir Stephen Powis [**INQ0014759]**, in 2023 NHS England recognised the need for an increased focus on neonatal services and, as one of a number of actions, this led to the creation of the position of National Clinical Director ("NCD") for Neonatal care. I applied for the role in August 2023 and commenced on 1 February 2024. The role acknowledges the clinical continuum of care between maternity and neonatal services as a single clinical pathway and provides leadership parity with obstetrics which already had an NCD.

9. The role of a NCD is to provide specialist clinical leadership and advice for NHS England, including driving transformation and supporting the commissioning of services. The job description was exhibited to the First Witness Statement of Professor Sir Stephen Powis [**INQ0014759**] and it sets out the key expectations for my role. It is broadly the same job description for National Clinical Directors of other clinical services, with the same expectations in respect of the job specifics, responsibilities, and key accountabilities.

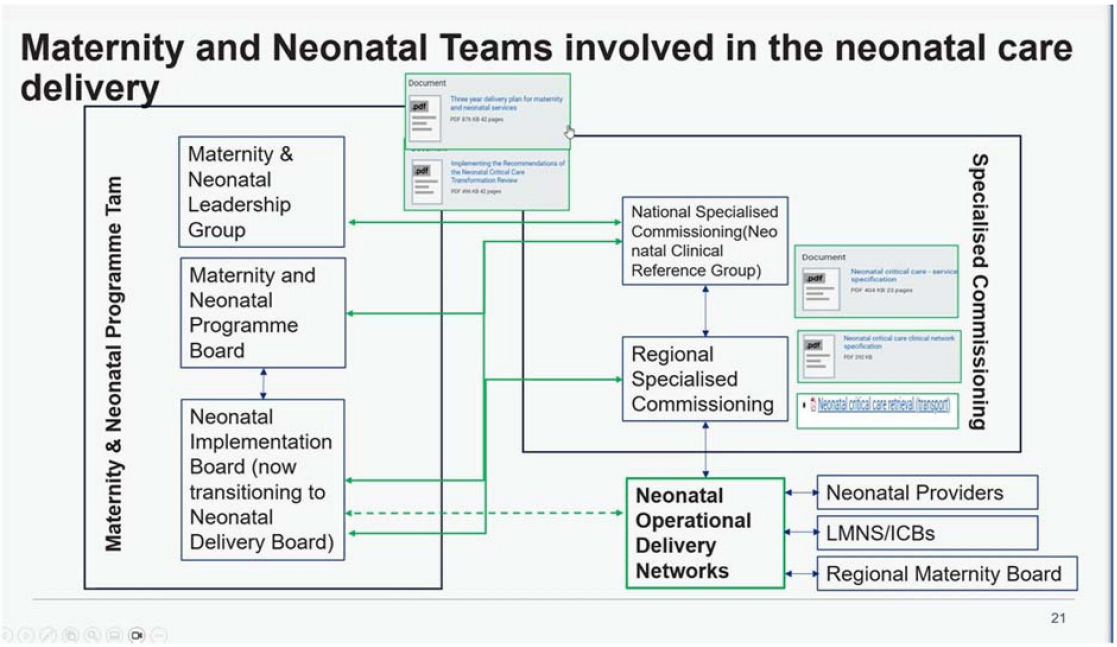
10. An overarching description of my role is to promote high-quality and safe care for neonates and their families and ultimately to support the Government's target of reducing stillbirths, neonatal and maternal deaths, brain injuries, and pre-term births. I am responsible for "ensuring effective, aligned and coordinated working with other clinical leads across the organisation…in their speciality area to ensure that all work programmes are aligned with national policy and strategy". I am accountable to the National Medical Director, via NHS England's Senior Leadership Team.

11. The role also involves supporting internal and external stakeholders and leading policy engagement. I provide neonatal clinical advice to national Specialised Commissioning and as such I have regular meetings with the specialised commissioning team - Matthew Day (Director of Clinical Commissioning), and Freddie Drew (Programme of Care Senior Manager) to discuss a range of issues that focus on neonatal care. Examples of issues discussed include a review of neonatal commissioning, neonatal data and an update of the neonatal specialised service quality dashboard.

12. Alongside Louise Weaver-Lowe Neonatal Nurse Lead, I also provide neonatal input to NHS England's Maternity and Neonatal Leadership Group, which includes Kate Brintworth (Chief Midwifery Officer), Donald Peebles (National Clinical Director for Obstetrics), Phoebe Robinson (Director of Maternity, Children and Young People) Steve Anderson (Deputy Director for the Maternity and Neonatal Programme) and other NHS England senior leaders. The Service User Voice Representatives for maternity, Catherine Brewster and for neonatal services, Kelly Phizacklea also participate as core members and provide essential input. The group aims to ensure there is a common understanding across national maternity and neonatal leadership of key issues, and that we are aware of significant reports and risk areas. We work collaboratively to ensure issues and challenges are handled collectively and sensitively. The Terms of Reference are exhibited at **NEO/2, INQ0108883**.

13. Figure 1 below sets the Maternity and Neonatal Teams in NHS England that are involved in neonatal care delivery. My role as NCD is to provide support and clinical leadership to these teams and the system as a whole.

Figure 1:



14. My role is part time, and I am seconded for 2 days a week to undertake the role of NCD and Chair of the Neonatal Clinical Reference Group. My day-to-day tasks vary hugely, but in general my main responsibilities can be summarised as follows:

a. Providing a source of leadership and neonatal expertise and advice nationally, examples of this include:

    i. Engagement with National Institute of Health and Care Excellence ("NICE")
    ii. Responding to coronial Regulation 28, Prevention of Future death reports that relate to neonatal care;
    iii. Raising safety alerts that relate to neonatal care with BAPM;
    iv. Contributing to frameworks for practice that support neonatal care;
    v. Convening neonatal specific forums to review neonatal aspects of national guidance e.g. Martha's rule;
    vi. Lead for neonatal safety actions that are part of the maternity incentive scheme, which is a program designed to enhance maternity safety within NHS Trusts

b. Providing strategic leadership and neonatal advice at meetings with Ministers and Secretary of State for health when required

c. Liaison with clinical leads of ODNs, network managers and regional commissioners;

d. Support for neonatal quality improvement through the National Neonatal Audit Programme;

e. Input into the spending review to provide key insight into neonatal care;

f. Meetings with various stakeholders to focus on neonatal care issues;

g. Supporting responses to Parliamentary queries;

h. Identifying and being made aware of neonatal trends and supporting change – an example of this is the improvement tool for Retinopathy of prematurity. I describe this example in more detail below (paragraph 48); and

i. Providing input and approval into policy documents e.g. the development of the Neonatal Care (Leave and Pay) Act. This is a landmark piece of legislation that will provide additional financial resources to families with babies in neonatal care and I was particularly honoured to have had a role in contributing to this work especially because of the direct impact it will have on families.

15. I feel my role provides visible leadership as well as increasingly becoming a formal and informal point of contact for the neonatal community. In addition, the National Clinical

Director role together with the NHS England Neonatal Nursing Lead also provides closer links between neonatal ODNs and national teams.

16. I attend a monthly meeting with other NHS England National Clinical Directors. This is not specific to neonatology, and functions as a forum for sharing of information from NHS England Medical Director. A number of meetings are face-to-face and are therefore useful for networking and sharing experiences with other NCDs. Topics have included a presentation on data, provided by the NHS England Director of Transformation, workforce issues and national supply chain escalation which are issues that have direct relevance to neonatal care.

17. I sit on the Maternity and Neonatal Programme Board, which provides direction to the Maternity and Neonatal Programme. The Terms of Reference are exhibited at **NEO/3, INQ0108884**. The programme aims to improve the care services provided by listening to women and families, supporting our workforce, developing and sustaining a culture of safety and meeting and improving standards and structures. I find this an effective forum in which to provide direction on neonatal matters and ensure it is aligned with other specialties. It also enables me to feedback updates of ongoing work to stakeholders.

18. In addition to this, I sit on various committees as part of the Maternity and Neonatal Programme. These are the Maternity and Neonatal Strategy and Policy Committee, the Maternity and Neonatal Programme Workforce, Training and Education Committee and the Quality, Performance and Surveillance Committee. These Committees support the programme to meet the goals and deliverables set out in the Three-Year Delivery Plan, including supporting systems, Trusts and staff to do the same. As the most senior neonatologist within NHS England, my voice on these Committees is invaluable and I ensure there is an adequate focus on neonatology and that the opinions of ODNs are well reflected. The Terms of Reference are exhibited at **NEO/4, INQ0108873, NEO/5, INQ0108879 and NEO/6, INQ0108882.**

19. Other regular meetings I attend include:

    a. A joint meeting with the NNA, BAPM, BLISS, and DHSC. These meetings are also attended by Ms Weaver-Lowe and senior colleagues from the maternity and neonatal programme. They are essential for understanding the priorities and concerns of the neonatal community. Recent items discussed include neonatal outreach, the response to the 10 Year Plan, safety champions in neonatology and the House of Lords Select Committee report on preterm births recommendations. I give feedback on various projects and may sometimes invite other staff to the

meeting to present on relevant work. I exhibit the agenda and meeting minutes from the two most recent meetings, 16 October 2024 and 8 January 2025. **[NEO/7, INQ0108875, NEO/8, INQ0108876, NEO/9, INQ0108881, NEO/10, INQ0108885]**

b. The Progress in Partnerships Maternity & Neonatal Group ("PiP"), which has representatives from Nursing and Midwifery Council ("NMC"), BAPM and the Royal College of Obstetricians, with Professor Donald Peebles (National Clinical Director for Maternity) and Kate Brintworth (Chief Midwifery Officer). This forum evolved from the Independent Working Group that was set up as one of the recommendations from the Independent Review of Maternity Services of The Shrewsbury and Telford Hospital NHS Trust. In November 2024, the Group decided to continue their work, and invited NHS England representatives to join **[NEO/11, INQ0108878]**. The group serves as a platform for professional bodies, colleges, frontline staff, and representatives of women's views to discuss ways to achieve effective and sustained changes in the care provided to women, babies, and families.

c. I have a close working relationship with BAPM who provide the neonatal expertise for RCPCH and as such my relationship with the RCPCH is mainly via BAPM. When broader involvement of child health issues are required, I discuss this with the RCPCH President.

20. My meetings with BLISS have been very productive and helpful. Their work is vital and they have a hugely important link with families. The additional information and support the charity sector provides to families is invaluable, and I think it is important for the NHS to work closely with the sector. I am currently supporting a BLISS campaign focussing on education and resources that are available for families of babies who born at term (after 37 weeks gestation). This is particularly important as although most babies born at term are healthy, about 60% of babies admitted to neonatal units are born at term. I remain keen to support their work and that of other charities that have a focus on neonatal care.

21. As NCD, I co-chair the Maternity and Neonatal Programme Equity & Equality Steering Group. The Terms of Reference are exhibited at **NEO/12, INQ0108880**. This group reflects one of the core aims of the Three Year Delivery Plan – to tackle health inequalities and make maternity and neonatal care safer, more personalised and more equitable. With my colleagues on the Board, we are developing strategy and working in partnership with NHS England and wider stakeholders to ensure productive implementation of projects relating

to maternity and neonatal equity and equality. This work is of paramount importance and my role as NCD enables me to gain insight into how the projects this Steering Group supports can improve neonatal care.

22. I have not yet met the CQC as part of my NCD role, but they are involved in many of the structures I have described throughout this statement. However, I have requested to join the next regular meeting between the Chief Midwifery Officer and the CQC to discuss neonatal unit inspections. These are often conducted alongside paediatric services, and in my opinion, neonatal services should be evaluated in conjunction with maternity services to support a perinatal care approach for families and their babies.

23. I maintain some clinical work and I believe that balancing this with my NCD role is beneficial. My clinical role provides me with access to clinicians, nurses and Allied Health Professionals working in neonatal services, allowing me to directly observe the impact of policy changes on care provided to babies and their families. I am also able to fully appreciate the issues and challenges of working in neonatology. In addition, neonatology is a technical specialty and therefore it is important for me to continue to work clinically to maintain my knowledge and skills.

Reflections on the NCD role so far

24. As I am the inaugural holder of the Neonatal NCD role, the last year has been focussed on embedding the role and reaching out to various stakeholders, which I am continuing to do. I have met with each of the regional specialist commissioning teams as well as representatives from Health Quality Improvement Partnership, NICE, Neonatal Audit Programme, NHS Impact, National Child Mortality Database ("NCMD"), National Institute for Health and Care Research. I have visited three neonatal services. I feel the role would benefit from more time than is currently allocated, and discussions are underway with NHS England on reflecting the time commitment required for this role.

25. Overall, I do feel that the role of neonatal NCD has helped to bring an increased focus on neonatal services across England, and some of the benefits of this increased focus are detailed below.

Three-Year Delivery Plan

26. The Three-Year Delivery Plan for Maternity and Neonatal Services was published in March 2023 and it brings together the work being done as a result of the Shrewsbury & Telford Report by Donna Ockenden, the East Kent Report by Bill Kirkup, and the Recommendations of the Neonatal Critical Care Review.

27. The plan strengthened the relationship between maternity and neonatal services bringing the required visibility to the neonatal aspects of the perinatal journey. The plan set out four themes and had neonatal ambitions integral to each of its workstreams:

    a. Listening to and working with women and families with compassion;

    b. Growing, retaining, and supporting our workforce;

    c. Developing and sustaining a culture of safety, learning, and support;

    d. Standards and structures that underpin safer, more personalised, and more equitable care.

28. The development of the Three-Year Delivery Plan has been positive and has provided a unified focus for the recommendations from a number of reports.

The Neonatal Critical Care Reference Group

29. As set out in paragraphs 113-117 of the First Witness Statement of Professor Sir Stephen Powis [**INQ0014759**], the Neonatal Critical Care Reference Group ("CRG") covers specialist neonatal services which provide care for all babies, usually, up to 44 weeks' corrected gestational age that require ongoing medical care in a neonatal critical care facility. I have been a member of the CRG since 2016 and became the Chair in 2020.

30. The purpose of any Clinical Reference Group is to support the commissioning of high quality and efficient specialised services and advise the national programmes of care on how specialised services should be provided. The Neonatal Clinical Reference Group is one of the 15 CRGs which sit within the Women and Children national programme of care. It is a multidisciplinary group that incorporates clinical expertise as well as the patient and public voice. Members include neonatologists, specialist commissioning, public health and allied health professionals. There are also a number of affiliate members which include clinical lead for Getting It Right First Time ("GIRFT"), neonatal ODNs, BLISS (a charity for babies born premature or sick), BAPM, and the Neonatal Nurses Association ("NNA"). The Terms of Reference are exhibited at **NEO/13, INQ0108871**. The membership and Terms of Reference are reviewed annually, and the group meets quarterly.

31. The CRG produces the Neonatal Service Specifications which are used by specialised commissioning teams in contracting clinical services and managing quality. In addition, the CRG produces the service specification for neonatal transport, and supports the paediatric surgery CRG with development of the neonatal surgery service specification.

32. The CRG also leads on the development of clinical commissioning policies and quality standards, provides advice on innovation, horizon scanning, service reviews and guides work to reduce variation and deliver increased value. They also ensure that any changes to the commissioning of specialised services focus on the needs of patients and the public.

33. As the Chair of the CRG, the Terms of Reference designate me a 'Core Member' and my role is to act as a point of contact for commissioners to obtain clinical advice and provide leadership to the CRG.

34. My role as Chair complements my role as NCD, as it enables me to ensure the work is not siloed and provides an important link between specialised commissioning of neonatology with the delivery of service. Sitting across the CRG, and the Neonatal Delivery Board (more detail below) enables me to do this. I feel it promotes effectiveness of delivery and ensures the two parts are well linked.

Neonatal Critical Care Service Specification

35. An updated Neonatal critical care service specification was published on 11 March 2024 **[INQ0018029].** It is the main commissioning document for neonatal services and sets out in detail the expectations for each neonatal service with respect to the following:

    a. Service models and pathways;

    b. Categories of neonatal care;

    c. Staffing;

    d. Professional Competence, Education and Training;

    e. Standards for Family Experience, Communication and Facilities;

    f. Obligations for neonatal units with respect to mortality reporting

        i. Neonatal deaths should be reviewed using the standardised framework of PMRT and the Child death overview panel, alongside maternity staff responsible for the care of the mother and with active communications with parents;

        ii. Each NNU should ensure adequate time in consultant job plans for a named clinical lead, a named education/training lead, each consultant providing educational supervision and for Perinatal Mortality Review Tool (PMRT) and Child Death Overview Panel (CDOP) reviews.

g. Neonatal patient safety and governance. This section of the service specification was strengthened, with requirements for providers to have:

   i. Guidelines, policies, and care pathways to ensure consistent and evidence-based clinical management which reflect national guidance;
   ii. Adopted ODN approved guidelines, operational policies and care pathways
   iii. Written clinical procedures and policies in place, including joint maternal and neonatal safety and governance processes;
   iv. Processes to review their NNAP, SSQD and MBRRACE data and develop plans to improve areas that require attention;
   v. Neonatal safety champions who must work with maternity safety champions to provide a perinatal safety culture and support board level safety champions. Trusts must support the neonatal safety champion in their role;
   vi. Process for sharing patient safety concerns with their ODN and must engage with ODN governance processes to raise concerns to the LMNS/ICB/NHS England region.

Neonatal Critical Care Review (NCCR)

36. The Inquiry is aware that in February 2016, the Better Births report set out the Five Year Forward View for NHS maternity services in England. This report highlighted several challenges facing neonatal services, including a lack of medical, nurse and allied health professional staff, nurse training, and insufficient cot capacity, and recommended a dedicated review of neonatal services. In response NHS England commissioned the Neonatal Critical Care Review ("NCCR").

37. The NCCR was undertaken by the Neonatal Clinical Reference Group of which I was a member, and the findings of the review were outlined in Neonatal Critical Care Transformation Review, which published their report on 13 December 2019 [**INQ0012352**]. Phase one of the NCCR comprised an evidence review undertaken by the NHS England Neonatal CRG across several work streams. Phase two of the NCCR focused on turning the evidence review into specific action plans for Regional Commissioning Teams, Neonatal Operational Delivery Networks and Local Maternity and Neonatal Systems ("LMNSs") to inform commissioner plans and, where required, service change.

38. The evidence review included a peer review of all neonatal units in England and will have included a review of Countess of Chester. It also reviewed data on neonatal activity and capacity. I undertook some of the peer review visits of neonatal units and chaired the data

and capacity sub-committee. The NCCR report set out three key commitments which were focused on:

a. Developing neonatal capacity;

b. Developing the expert neonatal workforce

c. Enhancing the experience of families through care coordinators and investment in improved parental accommodation.

39. To achieve these commitments, the NCCR made a series of recommendations and set out 10 actions for local and regional NHS bodies to transform neonatal services to improve the care of babies and experience of families. This was supported by funding from the NHS Long Term Plan. The actions set out in the Neonatal Critical Care Review report have been incorporated into the Three-Year Delivery Plan.

40. The NCCR also recommended that a national Neonatal Implementation Board would be established to oversee the delivery of the recommendations and action plans. This is described further below.

Neonatal Delivery Board

41. The Neonatal Delivery Board ("NDB") was designed to function as an additional work stream of the Maternity Transformation Programme, bringing together existing national programmes of work, as well as the initiation of new regional and national work to ensure the delivery of the commitments in the NHS Long Term Plan. The Neonatal Implementation Board was established in June 2019 and reported jointly to the national Maternity Transformation Board and the national Specialised Commissioning Delivery Group. I co-chaired the Neonatal Implementation Board with Matthew Day (Director of Clinical Commissioning, National Specialised Commissioning).

42. On 26 February 2024, the initial implementation phase of the Neonatal Critical Care Review was deemed to be complete, and it was proposed for the Neonatal Implementation Board to be scaled down, meet less frequently and be renamed the Neonatal Delivery Board ("NDB"), as it moved into the delivery phase. **[Exhibit NEO/14, INQ0108872]** From October 2024, the Neonatal Implementation Board has been referred to as the Neonatal Delivery Board to better represent the transition and future of the Board, and the updated Terms of Reference are exhibited at **NEO/15, INQ0108877**. I continue to co-chair the NDB with Matthew Day. The Board meets quarterly.

43. The NDB remains accountable to the Maternity and Neonatal Programme Board, overseeing the Maternity and Neonatal Programme. The NDB will primarily focus on

capital and infrastructure, workforce, assurance and service delivery. It will also take into account of the recommendations of public inquiries, including the Thirlwall Inquiry. As per the Terms of Reference, the NDB "continues to be responsible for overseeing the operational delivery and completion of the actions within the Neonatal Critical Care Review and providing support for the implementation of deliverables within the Three Year Delivery Plan".

Engagement with local clinical leads, workforce and networks

44. I have a working relationship with the clinical leads for the neonatal operational delivery networks as well as having a formal monthly meeting with the Neonatal ODN managers, regional specialist commissioners and ODN leads which is jointly chaired by me and Louise Weaver-Lowe (NHS England Neonatal Nursing Lead). The meeting is focused around sharing information on national work, implementing recommendations, and identifying where networks need further support. The Terms of Reference for this meeting are exhibited at **NEO/16, INQ010887 0** Neonatal critical care is provided at 155 sites (120 trusts) in England, and discussions about individual services take place at regional and ODN level.

45. Each of the 10 ODNs has a lead clinician, and I meet with them twice monthly, at a meeting known as the Neonatal Clinical Leaders Forum, which I established in August 2024. It was set up to provide an opportunity to network, to share good practice and raise issues as well as supporting me in getting to know each of the leads and their network areas.

46. The meetings serve as a platform for peer support among clinical leads and provide a forum for discussion. Clinical leads are senior clinicians within each neonatal network and share their knowledge and offer advice on emerging policies and issues, which supports my role as NCD. Additionally, the clinical leads have helped to increase neonatal representation and advocacy at national maternity and neonatal meetings by attending a number of key meetings.

47. There are examples of clinical leads and ODN managers raising issues at either the Neonatal Clinical Leaders Forum or the ODN managers meeting which has resulted in forums or additional policy to effect change. For example, following the implementation of the pilot of Martha's Rule in adult and paediatric services, the clinical leads raised that it was not being piloted consistently in neonatal services. This is now being reviewed, with the support of leads from networks that have more extensive experience of Martha's Rule. They also raised concerns with consistency of senior review of patients by senior clinicians in LNUs and SCUs. I contacted BAPM and a standard for patient reviews was incorporated into the guidance for clinical care in LNUs and SCUs.

48. Another example is the discussion around the emerging concern of a gradual reduction in the availability of paediatric ophthalmologists to undertake retinopathy of prematurity screening which will eventually have an impact on the service if not addressed. Retinopathy screening is a time critical review of the retina of a premature baby to assess if treatment is required to prevent future impact on vision. This was raised as a significant concern and is common across all ODNs. A project is now being undertaken by the National Improvement team to develop a retinopathy of prematurity toolkit which will look at alternative models to delivering the service using trained neonatal nurses, retcams[1], a multi-disciplinary team approach and a standardised training package. It is hoped that the toolkit will be piloted in two ODNs to review the model's suitability for providing a sustainable service. My role as NCD has enabled me to collaborate with the NCD for eye care to progress this development. It is unlikely to have happened if the NCD role was not in place.

49. In addition to the ODN network leads I have also met with the neonatal lead for Local Neonatal Units and Special Care Units. The issues faced by LNUs and SCUs can be different to those faced by NICUs, for example, rotas being shared with paediatrics, and neonatal nurses redeployed from neonatal care during periods of increased activity on paediatric wards especially in winter. There is also difficulty recruiting to nursing quality roles such as education lead, governance lead, workforce, bereavement and palliative care leads partly based on difficulty agreeing remuneration by local trusts but also availability and lack of nursing seniority/experience. Whilst this is also a concern in NICUs, it is much more of a problem on LNUs/SCUs and needs to be considered when developing policies and workforce plans in neonatal care. The Three-Year Delivery Plan has allocated 98 FTE neonatal nurse quality roles to support cot side clinical training and clinical governance.

50. In general, the Clinical Leaders Forum has been an excellent opportunity for leaders to share intelligence and ideas. In my view it is beneficial that I am in regular contact with the senior neonatal clinical leads. I believe that these personal connections are just as important as formal reporting structures. I would like to foster a culture within these forums where colleagues feel heard and supported when necessary.

Neonatal workforce – Conduct and leadership

51. Where there are concerns about conduct and leadership, the formal escalation route would be for staff to follow their local trust procedures including speaking to the Freedom to

[1] Imaging camera used in neonatal units to screen for retinopathy of prematurity.

Speak up Champion and raising concerns via their normal reporting structures in their employing organisations. If concerns were not progressed via internal routes within a provider, staff can also contact professional bodies for example NMC, GMC and the CQC.

52. Individual organisations and providers are responsible for local issues and are best placed to deal with them. Where serious concerns are raised about a professional's fitness to practice which could place patients at risk, or negatively impact public confidence in the professions, it would be reported to the NMC or GMC through their fitness to practise process.

53. ODNs do not have a statutory or regulatory function but have insights into the culture and performance of neonatal units as they do annual visits to units in their network, analyse data, provide annual reports and engage with neonatal services in a wide range of meetings and events. The neonatal safety champion at unit and board level could also be a source for raising concerns

Engagement with national bodies, policymakers and neonatal charities

54. The role of NCD for Neonatology involves engagement with senior policymakers both within NHS England and the DHSC advocating for neonatal services.

55. I do not have a regular meeting with the National Medical Examiner, but I met with him to discuss the guidance and expected standards for Medical Examiners prior to their implementation on 9 September 2024. The purpose of this meeting was to discuss the investigation of neonatal deaths within the medical examiner system, given the complexity of neonatal mortality as a speciality. I wanted to ensure that medical examiners who mainly work in adult specialties would have sufficient knowledge to adequately probe and question a neonatologist following a death of a baby ensuring the medical certificate accurately reflects the cause of death. In addition, it is crucial that there is an understanding of neonatal care, to prevent inappropriate referrals to the coroner.

56. In light of the above, my view at the time that I met with the National Medical Examiner was that neonatology would lend itself to having specialist neonatal medical examiners perhaps working across an ODN footprint. I remain interested to see how the system operates for neonatal deaths. I also recognise the National Medical Examiner's views as to the role of Medical Examiners and the need for them to have sufficient expertise across a range of specialities. I am aware that the National Medical Examiner is working with BAPM on specific guidance for neonates and I am supporting that work, which I think will be very helpful for medical examiners.

57. Additionally, I fully understand that the new guidance and expected standards need to be in place for a period of time to assess the impact, and my concerns may be theoretical. Overall, I think the implementation of the medical examiner system is very helpful and is a positive step.

58. I have regular contact with BLISS, as I have set our earlier in this statement. I have had in the past occasional informal contact with Spoons, a neonatal charity based in the North West of England, as the chair of the charity sat on the CRG as one of the service user representatives for three years. I do not have any other formal contact arrangements with any other neonatal charities, but I am very keen to have contact with other neonatal charities as they provide important insights on neonatal care from a different perspective.

Overseeing improvements in patient safety on neonatal units

59. Whilst I do not have any direct contact with the Patient Safety Commissioner, I am involved in various other strands of work relating to improvements in patient safety on neonatal units. Current examples of such initiatives include:

    a. Work to strengthen the role of the Neonatal Safety Champion at provider and network level. I am keen for staff to view the Neonatal Safety Champion as a way to report concerns. We are in the process of developing the role further and considering how to increase its visibility within organisations;

    b. Update of the PQSM and relaunch as the Perinatal Quality Oversight Model;

    c. Promotion of training programmes, including the NHS England Perinatal Culture and Leadership Programme; and

    d. Support of the development of the MOSS and real time data monitoring.

Perinatal Quality Oversight Model

60. Additionally, the Perinatal Quality Oversight Model ("PQOM") is in the process of being established and will replace the Perinatal Quality Surveillance Model, which was published in December 2020 [**INQ0018013**] is being reviewed currently to reflect new NHS structures (such as ICBs) and the integration and delegation of neonatal services across England.

61. The PQOM will have four levels: Trust, System, Regional and National. At each level varied information and data should be considered, including quantitative and qualitative data, and intelligence from maternity and neonatal services. Each level has its own set responsibilities and is accountable to NHS England or the government. The advantage of

the new model is that it better assigns responsibility of actions to certain bodies, meaning there are clearer lines of accountability.

62. It is currently envisaged that the PQOM will be published in spring 2025 and I can arrange for a copy to be sent to the Inquiry when this occurs.

NHS England Perinatal Culture and Leadership Programme

63. I participated in the NHS England Perinatal Culture and Leadership Programme, alongside Professor Donald Peebles (Obstetric NCD), Phoebe Robinson (Director for Maternity and Neonatal Pathway) and Kate Brintworth (Chief Midwifery Officer). This programme addresses the fact that inquiries and investigations have almost always highlighted cultural issues in underperforming units. The programme aims to foster good culture and strong leadership within organisations and promote multi-disciplinary team working. Each provider has sent a quadrumvirate of an obstetrician, midwife, a neonatal representative (medical or nursing) and an operational management representative to participate in the programme. Together with Donald, Phoebe, Kate and myself we represent the NHS England national equivalent of the organisational quadrumvirate.

64. The national quadrumvirate participated in the programme alongside provider attendees, I found the programme to be very effective and beneficial for leadership development – and one of the best leadership programmes I have had the opportunity to undertake. The focus was on the quadrumvirate dynamic, rather than individuals, and was designed to enable teams to take the learning and implement change within their organisations. There was a significant emphasis on teamwork and participating alongside provider quadrumvirates demonstrated the national quadrumvirate's commitment to this work.

Neonatal Data

65. The UK has long been an international exemplar for population-level national neonatal data collection. These data sets have benefitted local, regional, national audit, quality improvement, service evaluation, commissioning and research to inform improvements in neonatal care. Two main contributing factors that made it feasible to bring together neonatal population-level data are:

    a. the majority of neonatal care being provided as NHS commissioned care, with associated consistency in service specifications, reporting and audit;

    b. a common Neonatal Electronic Patient Record System (EPR) ("BadgerNet") that was introduced nationally in 2007 and, although not mandated for use by neonatal units, all neonatal units in England adopted it.

66. BadgerNet enabled the efficient flow of data from neonatal units to the two main national repositories of neonatal data, namely the National Neonatal Audit Programme ("NNAP"), which is commissioned by Healthcare Quality Improvement Partnership and managed by the Royal College of Paediatrics and Child Health, and the National Neonatal Research Database ("NNRD") (managed by Imperial College London). This is supported by data storage and sharing agreements governed by appropriate regulatory approvals. NHS England is not directly involved in these arrangements, although supports the clinical audit programme and I am aware that this is explained in the First Witness Statement of Professor Sir Stephen Powis [**INQ0014759**].

67. There is a challenge, however, in ensuring that these established data flows continue to operate effectively as hospitals nationwide implement hospital-wide Electronic Patient Record ("EPR") systems in alignment with the NHS's ambition to fully digitalise healthcare services. Enabling interoperability between new hospital-wide EPR systems and existing service-specific systems, such as BadgerNet, is an area of ongoing focus, not just in neonatal care.

68. In my clinical practice, I am aware of the issues for staff if there are multiple data entries required and also of the risk that not all relevant data is entered onto each system, and in my experience, limited Interoperability hinders data sharing and collaboration across networks and with national initiatives.

69. I have been working to support the understanding of these issues and the development of potential solutions. This has included convening a group of neonatal data experts to come together over the summer and autumn of 2024 to share their experience and explore potential options. The group is relatively informal for now. I co-chair it, along with David Cox (Consultant Neonatologist at Great Ormond Street Hospital for Children NHS Foundation Trust and Clinical Lead for Digital Child Health, NHS England). This group will include representatives of ODN data managers, ODN Clinical Leads, BAPM, programme manager Maternity Transformation Programme, EPR user group.

70. As a group, we have been able to contribute specific neonatal questions to the annual Digital Maturity assessment that is sent to each NHS providers Chief Clinical Information Officer. This will be helpful in providing further clarification and insight on neonatal data issues.

71. I also prepared a paper for the National Director for Transformation setting out a summary of the issues and the options. This paper was sent on 26 June 2024 and is exhibited at **NEO/17, INQ0108874**.

72. However, as will be apparent from this paper, there is no easy solution to the issues and further work is needed to understand how best to address them, including funding for such solutions. I will continue to support this ongoing work.

73. Longer term, I think that developing a neonatal record standard that ensures data collection for neonatal patient care is standardised and consistently records information about patient care would be helpful.

74. I also think that greater integration between maternity and neonatal care data would also be beneficial, including potential linkage of the main audit programmes in perinatal and neonatal care that are currently run on a service-specific basis. Linkage between maternity, neonatal, community and paediatric health, education and social services data would support evaluation of long-term outcomes. Research has consistently demonstrated that these outcomes are important to parents, are vital for counselling, informing resource needs and research to explore optimal neonatal interventions.

Concerns regarding effectiveness of culture, governance and management structures in the NHS

75. Delegation of neonatal services has the potential to provide benefits with regards to integrated pathways of care between maternity, neonatal and paediatrics, which are important fundamental objectives for the NHS. Patients could receive more joined up care, for example extending neonatal outreach, with better care to support patients who can be discharged earlier. Population based budgets means decisions on spend are based on the needs of a local population rather than specifically on activity in hospitals. This may be an area where Integrated Care Boards can help enable further integration as they take-on delegated commissioning and thereby support the closer alignment of hospital and community services

76. Shortly after my appointment as NCD, together with leads from commissioning, nursing and patient representative, I undertook an engagement exercise with all the regions in England introducing ourselves and setting out our roles. This was also an opportunity to understand the challenges in each region and understand the landscape from a regional perspective.

77. For the three regions that have been working with delegated arrangements, feedback has indicated that the new processes are more difficult to manage as there are more layers of decision making and a lack of expertise regarding neonatal services, it appears that some efficiency has been lost. This not specific to neonatal services and I understand similar

feedback has been received by other delegated services. This is being fed back to the national specialised commissioning team, to understand how ICBs can best be supported.

Clinical aspects of Neonatal care

Neonatal Outreach

78. Neonatal Outreach is the ongoing care provided at home by neonatal services following the discharge of babies from the neonatal unit. Neonatal outreach into the community should not be seen as a separate entity but as part of the continuum of neonatal care delivered post discharge. It allows earlier discharge of babies with safe support in the community; however outreach services are not currently consistently commissioned and therefore there are large variations in the provision.

79. Outreach includes short-term nasogastric tube feeding at home, home oxygen therapy, and home phototherapy programmes. In some regions outreach services are well established, whilst in other areas there is no provision at all. Establishing outreach consistently across all regions would be hugely beneficial in ensuring babies across the country are well cared for. The period following discharge home can be a difficult period, and specialist support for babies and families at this time provides multiple benefits, including reduction in baby-parent separation, which reduces separation anxiety, improved outcomes for babies, and reduced length of neonatal stay in hospital. It is also felt to reduce readmissions back into hospital.

Pharmacy support for neonatal units

80. Medication errors account for a significant proportion of patent safety incidents on neonatal units. All medications are weight based and patient weights vary by more than 10-fold (from 400g up to 6000g and occasionally outside these parameters). There is also the requirement for complex drug calculations on a regular basis. The Neonatal GIRFT report found that 62% of neonatal units had medication issues in the top three reasons for incident reports, but despite this only 19% of units had electronic prescribing. Interventions to reduce medication errors in neonatal care include electronic prescribing, standardised prescribing, use of electronic clinical calculators, 'smart' pump technology, education and training, pharmacy-prepared ready to use drugs/infusions. In my opinion the implementation of these interventions will support medication safety

81. The presence of an experienced neonatal pharmacist in the neonatal unit will also support medication safety.

82. I have also contributed to (and will continue to do so) NHS England's review and further work around insulin safeguards on neonatal units.

Concluding remarks

83. The opportunity to provide leadership to the neonatal community in England is highly rewarding and I consider it a privilege to have a role that impacts families, clinicians and the broader neonatal community. I care deeply about improving neonatal care, and my role as NCD has granted me the opportunity to lead this work. Through my role as NCD and my clinical work, I am aware of the commitment and dedication that neonatal staff have for improving the outcomes for babies in their care.

84. Neonatology is a complex specialty that I feel has benefitted from having senior representation within NHS England by having a consistent point of contact for stakeholders, policymakers and senior officials to engage with.

Statement of Truth

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: ___10 February 2025_____