

- i. Witness Name: Dr Eleri Adams
- ii. Statement No.: First
- iii. Exhibits: EA/1-9
- iv. Dated: 16 February 2024

THIRLWALL INQUIRY

WITNESS STATEMENT OF Dr Eleri Adams

I, Dr Eleri Adams, will say as follows: -

Section 1 – About BAPM

2. I am writing this statement as current President of The British Association of Perinatal Medicine (BAPM). BAPM is a professional association and registered charity. Established in 1976, the group used the word 'Perinatal' (the period around the time of birth) rather than 'Neonatal' (first 28 days of life, or longer if born early) in the title to stress the importance of fetal life before birth, and to indicate that members were working in maternity rather than children's hospitals. In the early years, the membership of the organisation was made up of a mix of obstetric and neonatal professionals. In more recent years, BAPM membership overwhelming consists of those working in neonatal care since other groups aimed specifically at fetal medicine and intrapartum care specialists now attract more of our obstetric colleagues.
3. BAPM's aims are to improve standards of perinatal care by supporting all those involved in perinatal care to optimise their skills and knowledge, promote high quality, safe and innovative practice, encourage research, and speak out for the needs of babies and their families.
4. BAPM is a membership organisation currently representing more than 2,000 professionals including doctors, nurses, ANNs, midwives, managers, allied health professionals, pharmacists, psychologists and parent / carer reps.

Member type	Number	%
Consultant	780	35%
Trainee	398	18%
Nurses / AHPs	616	27%
Retired	23	1%
Student	243	11%
Parent	92	4%
Honorary	89	4%
Total	2241	100%

Fig 1: BAPM Membership breakdown from January 2024

5. BAPM's reach and profile has continued to grow, and in the last five years BAPM has become the go-to organisation for standards and advice on neonatal care. BAPM frameworks for practice and quality improvement toolkits for neonatal care are used by UK-wide health services (including NHS England), neonatal networks, and individual trusts, to support change and improvement in neonatal care. BAPM also plays a significant advocacy role on behalf of neonates and their families at a national level, as well as providing training and educational events through webinars and conferences which attract an international audience.
6. BAPM employs three members of staff that run the office, a full-time Chief Executive, a part time Finance and Membership Coordinator and a part time Communications Officer. The majority of BAPM's work programme is delivered by members acting on a completely voluntary basis.
7. Anyone with an interest in perinatal care is welcome to join BAPM as a member. Up until September 2016, membership required the completion of an application form which asked for support from two existing members and all membership applications were approved at the AGM. In December 2015 BAPM had approximately 900 members. Since 2016, anyone can join by completing an application form and paying the relevant membership fee (where applicable), without requiring nominations or AGM approval. Membership applications are now managed entirely online. There has been a significant growth in both the number of members and the breadth of health professionals and service users represented within BAPM membership.

8. The Executive Committee roles are included in BAPM's constitution. Any changes made to these roles need to be agreed at BAPM's Annual General Meeting (AGM). The committee roles in place at the September 2015 AGM were as follows:

- President
- Honorary Secretary
- Honorary Treasurer
- Representative for Scotland
- Representative for North of England
- Representative for South of England
- Representative for Ireland
- Representative for Wales
- Representative for Nursing / Midwifery
- Representative for Parents and Carers (ex Officio)
- Representative for British Maternal & Fetal Medicine Society (BMFMS) (ex Officio)
- Deputy Representative for Scotland
- Deputy Representative for North of England
- Deputy Representative for South of England
- Deputy Representative for Wales
- Deputy Representative for Nursing / Midwifery

9. The committee roles have been updated several times since then to better reflect the priorities and ways of working for the organisation. The current committee roles are as follows:

- President
- Honorary Secretary
- Honorary Treasurer
- Quality Lead
- Data Lead
- Research Lead
- Education and Wellbeing Lead
- Safety Lead
- Equality, Diversity and Inclusion Lead
- Family Advocacy and Support Lead
- Representative for Networks

- Representative for AHPs
- Representative for Nursing
- Representative for Midwifery
- Representative for LNU/SCU
- Representative for Trainees and Students
- Representative for Parents and Carers (ex Officio)
- Representative for British Maternal & Fetal Medicine Society (BMFMS) (ex Officio)

10. Appointments to the Executive committee are for 3 years. Any vacancies, usually arising from people coming to the end of their three-year term, are advertised to the membership in advance of the AGM. Any ordinary member of BAPM (a consultant, trainee, or 'other' member) is eligible to apply for a vacancy. When more than one member applies for a vacancy, the appointment to the role is made to the person with the highest number of member votes. All appointments are formalised at the subsequent AGM.

Section 2 – BAPM Documents (including Frameworks for Practice.)

11. BAPM working groups are committees of members tasked with producing an output, usually a framework for practice or a quality improvement toolkit to be used by healthcare professionals on a specific aspect of neonatal care. Topics for these frameworks or toolkits are proposed by members and prioritised by the Executive Committee.

12. Working group members are volunteers and receive no form of payment, although expenses are covered for face-to-face meetings. Most group members come from the wider BAPM membership or are representing a specific organisation. The process for determining working group membership has evolved and become more formalised over time. The current process involves the development of a terms of reference for each working group identifying key roles, individuals and stakeholder groups that will have expert knowledge on the topic in question. Vacancies for individuals are advertised to BAPM members and the wider neonatal community and the chair will assess the anonymous applications and select members to join the working group. Other stakeholder groups such as professional societies will be contacted and asked to provide a representative to send to meetings. These

- representatives will be asked to act as a liaison between their professional group and the BAPM working group.
13. Prior to 2020, meetings were conducted face to face, but since the widespread implementation of Microsoft Teams during the Covid-19 pandemic, almost all work is done via online meetings.
 14. Where there is evidence available this is included and referenced, however, many BAPM documents cover topics where there is not always clear evidence for a specific course of action. Therefore some recommendations in BAPM documents are agreed by consensus of the working group and this is indicated in the document. The groups will produce a draft document which is then shared for consultation with BAPM members and stakeholders. Documents are publicly available on the BAPM website and anyone is able to respond to the consultation. The standard consultation period is 6 weeks. Following the consultation, a final version of the document is agreed and published. Frameworks and quality improvement toolkits are reviewed every 5 years, or sooner, if new evidence shows that practice needs to change.
 15. BAPM frameworks set standards of practice based on best available evidence and consensus. Whilst these frameworks are often considered by the neonatal community as standards for best practice, there is no statutory obligation for trusts to implement them, and whether and how frameworks are implemented locally is up to individual networks and trusts. However, national bodies often adopt standards set by BAPM which then become more enforceable eg. NHS England has adopted BAPM staffing standards into their [national service specification](#).
 16. All BAPM documents are reviewed every 5 years as part of our review cycle, but if BAPM is made aware of any new evidence meaning that the document is out of date then it may be revised sooner.
 17. BAPM also undertakes other activities in addition to developing frameworks. The following table is taken from BAPM's annual report 2016 and summarises the key pieces of work carried out in the previous year against the organisation's objectives from that time:

Objectives

Activities undertaken financial year 2015- 2016

Publishing standards and providing guidance on good management and care	• Publication of 'Newborn Early Warning Trigger & Track (NEWTT) - a Framework for Practice' (May 2015) • Publication of 'Use of Central Venous Catheters in Neonates - a Framework for Practice' (Dec 2015) • Publication of 'Fetal and Neonatal Brain Magnetic Resonance Imaging: Clinical Indications, Acquisitions and Reporting - a Framework for Practice' (Feb 2016)
Providing postgraduate education meetings throughout the year	• Delivery of the Perinatal Session at RCPCH's annual Spring Meeting (April 2015) • BAPM's Annual Perinatal Trainees' Meeting (October 2015) • BAPM's Annual General Meeting (November 2015)
Promoting research and academic excellence	• BAPM's Multiprofessional research skills training day (October 2015) • Publication of article on Research Skills Training in Archives of Disease in Childhood • Representation on NIHR CRN Neonatal Clinical Studies Group (ongoing) • Representation on RCPCH Research Consultation Committee (ongoing) • Cataloguing of Peter Dunn library resource (ongoing) • Working with Chiesi to provide educational bursaries (ongoing)
Advising on training and education in perinatal practice	• BAPM's Annual Perinatal Trainees' Meeting (October 2015) • RCOG Specialist Societies Liaison Group (ongoing) • Infant Journal - Working Together to raise awareness of patient safety issues (ongoing) • Trainee representation on EC
Providing advice to Government and other professional bodies on developing and improving perinatal care	• Contributing to NHS England Maternity Review (Feb 2016) • Representation on Neonatal Critical Care Clinical Reference Group (CRG) and Fetal Medicine CRG (ongoing) • RCPCH - Part of Invited Reviews Team (Ongoing) • Contributing to Scotland Maternity and Neonatal Services Review (ongoing)
Raising awareness of, and proactively influencing the policy environment, in which perinatal care is delivered	• Contribution to Bliss Baby Report (Oct 2015) and Transport report (Apr 2016) • Representation on BMFMS Executive Committee (ongoing) • Newly appointed representative from Local Neonatal Units and Special Care Units on EC
Auditing and monitoring the outcome, structure and function of perinatal care for babies and their families	BAPM working groups that met in 2015/16: • Family Engagement • Donor Expressed Breast Milk • Neonatal and Fetal MR Brain Imaging • Central Venous Catheters (with NHS England) • Interaction with Commercial Organisations (Ethical Framework) • Neonatal Mortality Review • Newborn Early Warning Trigger & Track (NEWTT) • Parenteral Nutrition • Quality Ongoing liaison and partnership work with: • National Neonatal Audit Project (NNAP) • Neonatal Data Analysis Unit (NDAU) • MBRRACE-UK • Neonatal Transport Interest Group • Neonatal Networks Group
Auditing and monitoring the outcome, structure and function of perinatal care for babies and their families	• Delivery of Neonatal update at RCPCH Progressing Paediatrics (Sep 2015) • Annual Neonatal Networks Meeting (Nov 2016) • Email bulletins, Website, Twitter, networking opportunities during meetings (Ongoing)

Figure 2: BAPM's activity summary 2015-16

18. Following a meeting of the Executive Committee in 2017 it was agreed to update BAPM's strategic aims to the following which are still used by the organisation to date:

- To help deliver high quality perinatal care
- To provide support and advocacy for perinatal professionals
- To promote research and innovation in perinatal care
- To provide advocacy for babies and their families

19. Examples of BAPM's current key activities include:

- Development of frameworks for practice and toolkits, running conferences and webinars. Monthly updates on neonatal news in newsletters to members.
- Development of reports on key topics important to members, sending representatives to national meetings, responding to external reports and writing to policy and decision makers to advocate for our members' views.
- Showcasing research at our meetings through talks and posters, taking part in research prioritisation exercises, creation of resources to help health care professionals get started in research.
- Working closely with Bliss and parent charities on our work programme, inclusion of parent and carer views into BAPM work programme.

Section 3 – BAPM's relationship with RCPCH

20. BAPM is an independent organisation with separate governance from the Royal College of Paediatrics and Child Health (RCPCH). BAPM receives no external funding, the organisation's income almost entirely comes from membership fees and profit from events.

21. BAPM is recognised as a Specialty Group of RCPCH (an independent body representing paediatricians practicing in a specific specialty of paediatrics for which a specific training pathway and lifelong education have been set up and overseen by the RCPCH). RCPCH is responsible for the training curriculum and assessments for doctors in training and BAPM is not directly involved with setting those standards and competencies: RCPCH also has a much broader involvement in child health both within and outside the UK.

22. The majority of BAPM's doctors will also be members of the RCPCH but BAPM's membership also includes other health care professionals such as nurses, pharmacists, psychologists and allied health professionals with neonatal expertise (primarily occupational therapists, speech and language therapists, physiotherapists and dieticians) that may be members of other royal colleges or professional organisations.

23. BAPM also has a service contract with RCPCH where we pay a fee to the organisation and they administrate some services for us (such as HR, Payroll, desk and meeting space).
24. Dr Alan Fenton (BAPM President 2014-2017) outlines the relationship between BAPM and RCPCH during the period of his presidency as follows. "If the Vice President or President of the College were approached about specific issues that were felt to require a neonatal rather than paediatric response, they would be passed to BAPM. Clearly this would depend on who was approached at the College, since Professor Neena Modi was President at that time and as a Neonatologist would potentially have been able to address such issues herself."
25. The relationship between BAPM and RCPCH has become closer over the last few years and BAPM now works more collaboratively with RCPCH in relation to specific areas of care affecting babies and their families. We share information, responses to external policy updates and communications between BLISS, BAPM and RCPCH to ensure joined up working. RCPCH are likely to suggest a response from BAPM where their expertise is very specifically within neonatology and conversely, BAPM will involve RCPCH where the area of expertise is outside neonatology.

BAPM's work on safety

26. BAPM is sometimes contacted by coroners and Maternity and Newborn Safety Investigation Programme (MNSIP), formerly part of the Health Safety Investigation Branch (HSIB), when they believe there is something that can be learnt from a neonatal death and they wish this learning to be passed onto BAPM members. When a safety issue or learning point has been raised with BAPM following contact from the Coroners' Office, NHS England National Patient Safety Team or Maternity Neonatal Safety Investigations Programme, formerly Health Services Investigation Branch (HSIB) report, this can be shared with BAPM members using our communication channels. These include a direct email to our members and adding details to the BAPM [website safety pages](#).
27. BAPM has previously commented as a stakeholder on thematic reports produced by HSIB. However, BAPM is not resourced, either in terms of personnel or finances, to provide formal input to HSIB individual case reviews, particularly as this might result

in conflicting opinion(s) from those of their contracted neonatal experts. BAPM wrote to HSIB in 2022 to clarify this position.

28. Communication with the former BAPM president, Dr Alan Fenton, indicates that during his tenure he recollects that BAPM were approached by the Care Quality Commission (CQC) to provide input into a thematic review undertaken by a large multidisciplinary team. This resulted in publication of a report "[Identifying and managing clinical risks in newborn babies and providing care for infants in the community who need respiratory support](#)" which was published in July 2016.
29. BAPM also produced a Framework for Practice "[Use of Central Venous Catheters in Neonates](#)" in response to a section 28 request following a Coroner's inquest. Originally published in 2015, the 2018 version of this document was revised following several case reports of fatal outcomes associated with central venous catheters. BAPM was contacted by NHS England Patient Safety Team to review the guidance with the aim of reducing harm and improving safety. In 2023, NHS England Patient Safety Team have requested that management of surgically inserted central venous lines is also included in the revised Framework which is currently being reviewed.
30. Dr Fenton stated that the only other safety-related 'work' undertaken by BAPM in 2015-16 was to encourage the membership to alert BAPM if safety issues arose around individual cases, so BAPM could anonymise the cases and disseminate learning. However, at this time it was met with limited success and was stopped. In 2019 the [Safety Stories web page](#) was initiated on the BAPM website and a few stories were shared in 2019-2020 but nothing more recently.
31. In May 2022 BAPM Produced "[Sudden and Unexpected Postnatal Collapse: A BAPM Framework for Reducing Risk, Investigation and Management](#)." This document takes account of recommendations from the Healthcare Safety Investigation Branch (HSIB) National Learning Report on Neonatal Collapse alongside Skin-to-skin Contact and HSIB were involved in the development of the Framework for Practise.
32. BAPM has been asked to respond to a coroner's report in 2023 to comment on a perceived discrepancy in neonatal guidance from NICE. The organisation has also

- provided a response to the HSIB report on recommendations on neonatal resuscitation (contributed via RCPCH) following a neonatal death.
33. BAPM has taken on a number of projects in the last few years related to safety including the development of [toolkits](#) to support key areas identified as needing improvement by the National Neonatal Audit Programme (NNAP).
34. BAPM has also recently revised the [Newborn Early Warning Trigger and Track \(NEWTT\) framework and chart](#). NEWTT was published in April 2015 and [NEWTT2](#) was published in January 2023. This chart is used to identify neonates who are deteriorating in postnatal care settings. The 2023 chart encompasses parental concern to acknowledge the importance of the opinion of the family in addition to the wider multi-disciplinary team. The inclusion of parental concern supports the recommendations made in recent national maternity investigations. An England-wide rollout of NEWTT2 was supported by NHS England's Maternity and Neonatal Safety Improvement Programme (MatNeoSIP) who have provided additional resource to support implementation of the tools across England and the development of an e-learning course.
35. The framework includes a list of at-risk groups that should be monitored using the NEWTT2 observations:

Appendix 1: Newborns for NEWTT2 monitoring

(see Page 5 and 6 of the main document for full details including frequency, duration and national guidance)

Intrapartum Fetal compromise (see hypoglycaemia) Meconium-stained amniotic fluid
Mode of Delivery Elective pre-labour Caesarean section <39 weeks' gestation Newborns born before arrival of a healthcare professional (BBA)
Early Onset Infection Risk factors Clinical indicators During treatment
Hypoglycaemia risk (BAPM framework) $\leq 2^{\text{nd}}$ centile and/or clinical wasting IPPV at 5 min of age, low cord pH ≤ 7.1 , low Apgar score ≤ 7 @ 5 minutes, Base deficit ≥ 12.0 Maternal B-blocker medication Maternal diabetes mellitus 34+0-36+6 weeks gestation Hypothermia unresponsive to thermal care Feeding concerns – reluctant, refusal, irritable, frequent feeder or any deterioration
Transitional Care (BAPM framework)
Postnatal concerns Early-onset jaundice <24 hours Grunting Feeding concerns - reluctant, refusal, irritable, frequent feeder or any deterioration Reduced tone Altered behaviour NB. Bilious vomiting is abnormal and immediate escalation is warranted
*Other maternal medications Maternal opiates <6 hours prior to delivery Prescribed maternal SSRIs and SNRIs and other psychotropic medications within the 3 rd trimester Maternal drugs of addiction – prescribed or illicit
*Consider using NEWTT2 if no other chart available or there are physiological concerns

This list is not exhaustive and NEWTT2 can be used as a track and trigger tool for other newborns.

Figure 3 Newborns for NEWTT2 monitoring

36. BAPM also contributes to a large number of external meetings related to safety where neonatal input is needed. BAPM's representative was involving in writing the neonatal element of the Saving Babies Lives Care Bundle version 3 (SBLV3).

Resources in support of the implementation of the recommendations in SBLV3 are freely available on the [BAPM website](#).

37. BAPM also sends representatives to several external safety related groups:

- Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries (MBRRACE-UK)
- National child mortality database (NCMD)
- Independent Maternity Working Group (IMWG)
- Maternity and Neonatal Safety Improvement Programme Steering Group (MatNeoSIP)
- Neonatal Clinical Reference Group (CRG), NHS England
- Special Health Authority Stakeholder Engagement Group Meeting
- Maternity & Neonatal New Action Forum
- Maternity Transformation Stakeholder Council
- Maternity and neonatal programme: Strategy & Policy
- Neonatal implementation board (part of Maternity Transport Programme)
- Quality, Performance and Surveillance (QPS) Committee (Maternity and Neonatal Programme)
- Reading the Signals - Outcome data
- Reading the Signals - Coordination Group
- National Maternity and Perinatal Audit Clinical Reference Group
- Diagnosis of Death - Ancillary Investigations
- Registration of Stillbirths before 24 weeks (Royal College of Obstetrics and Gynaecologists)
- Expert case review group (Diagnosis of death)
- Diagnosis of Death - RCPCH Guideline (Royal College of Paediatrics and Child Health)
- Neonatal Programme Board / Neonatal partnership board
- National Neonatal Audit Programme (NNAP) Board
- NNAP Data and Methodology Group
- Perimortem Caesarians – (Resuscitation Council)
- Palivizumab - Expert Advisory Group
- Infection in Critical Care Quality Improvement Programme (ICCQIP) Board

Section 4 – Independent Reviews

38. BAPM does not conduct independent reviews and we do not feel we have the infrastructure support to do this. The RCPCH has an invited review programme and BAPM's only involvement has been limited to supplying the names of individuals to be approached to take part in a review when the RCPCH were not able to find reviewers through their own contacts. BAPM supplied the names of these reviewers simply on the basis of what level of neonatal unit they worked in.
39. In 2015-16 BAPM did not maintain a register of members who might undertake review work and did not provide advice or training for those who wished to do so. Former President Dr Alan Fenton confirmed that to the best of his knowledge, BAPM was not asked to supply names for the Countess of Chester review in 2016. The BAPM Office have also searched their electronic files and confirmed that they can see no record of BAPM being contacted about this.
40. Prior to 2023, when asked by other organisations for reviewers, we have passed on advertisements to our membership to respond to these organisations directly. Their involvement was on an individual basis and not on behalf of BAPM.
41. Due to an increasing number of requests for neonatal expertise to contribute to reviews, in 2023, BAPM compiled a list of members interested in being contacted about external reviews and who were able to self-certify that they met certain criteria and to give permission for their information to be released to appropriate third parties. We plan to update this list on an annual basis. The criteria is outlined below:
42. Essential Criteria to join BAPM's Independent Reviewer Register

For Medical Staff:

- You must be currently working in clinical practice in the UK or have retired no more than two years previously.
- You must have been a UK consultant for at least 10 years. (For those with consultant level experience outside of the UK, you should have at least 5 years' experience as a consultant in the UK and at least 10 years' total experience at consultant or consultant equivalent grade.)

- You must be on the General Medical Council (GMC) specialist register for Paediatrics (Neonatal Medicine).
- You must have no restrictions to practise or pending fitness to practise investigations from GMC or other regulatory body.
- You must be a current member of BAPM.

43. For Nursing Staff:

- You must be working in clinical practice in the UK or have retired no more than 2 years previously.
- You must have been a UK registered nurse for a minimum of 10 years.
- You must hold, or have held, a band 7 post or above for a minimum of 5 years.
- You must be on the NMC register, with no restrictions to practise or pending fitness to practice investigations.
- You must be Qualified in Speciality (QIS).
- You must be a current member of BAPM.

Section 5 - Neonatal Data

44. The following infographic shows a timeline of neonatal data developments.

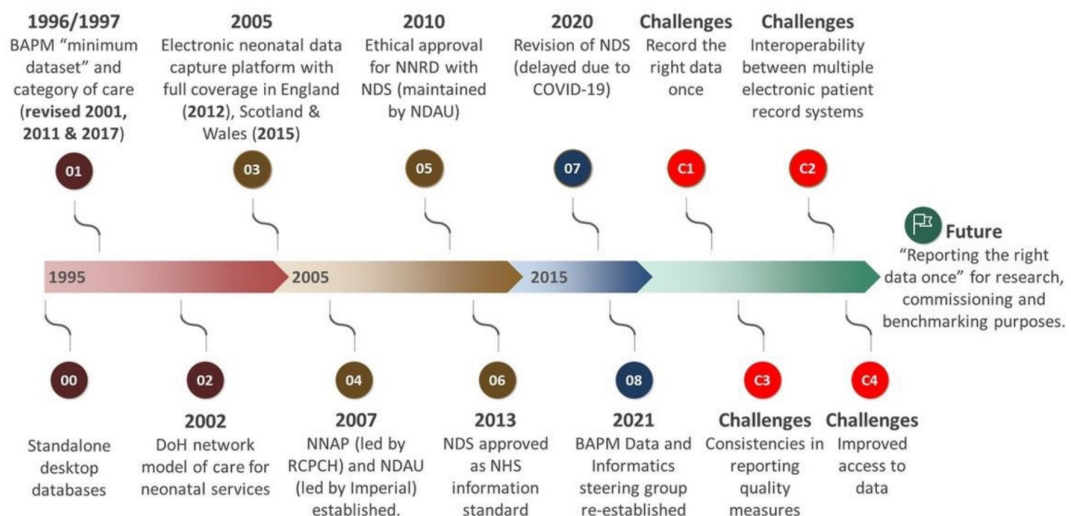


Figure 4 – timeline of neonatal data developments

45. BAPM does not hold information about all the organisations, databases and audit programmes dealing with neonatal data between 2015-23. However, the key organisations dealing with neonatal data between 2015-2023 are outlined in BAPM stakeholder group below. The Data Landscape article provided as an attachment also provides good background information on neonatal data during this time. There are different data flows for neonatal data within each of the UK's four nations. Diagram showing the current data flows are available on the [BAPM website](#). EA/1: INQ0012954
46. The BAPM Minimum Data Set (1996/7 and revised 2001, 2011 and 2017) outlined key items for data collection. BAPM also developed a Categories of Care document that outlined the procedures and types of care that determine, on any given day, whether a baby is receiving intensive (highest level), high dependency care (medium level), special care (lowest level) or transitional care (lowest level care given with the carer present). BAPM had no role in the collation or audit of these data.
47. The BAPM Minimum dataset has now been superseded by other NHS-approved information standards and national datasets such as [Neonatal Critical Care Minimum Data Set \(NCCMDS\)](#) in 2016 and the [neonatal dataset \(NDS\)](#) in 2014 (updated 2022), and the National Neonatal Audit Programme (NNAP).
48. The data items for the categories of care were developed into the Neonatal Critical Care Minimum Data Set (NCCMDS) by NHS National Casemix Office (now part of NHS Digital) to form the specialised Neonatal Health Resource Groups (Neonatal HRGs). Subsequent revision of the NCCMDS to create NCCMDS version 2 were developed by a large multiprofessional group led by me as chair of Neonatal Critical Care Review (NCCR) Pricing work and which included BAPM representation. The subsequent NCCMDSv2 was endorsed by BAPM as an update for the Categories of Care in 2016. BAPM is looking to revise the Categories of Care document in the next year.
49. All neonatal units in England, Wales and Scotland have used a single system for data collection (BadgerNet) for many years (since 2012 for England and 2015 for Scotland and Wales). BadgerNet captured the data required for both the minimum dataset and the BAPM categories of care.
50. BadgerNet is not a live full electronic patient record (EPR) system in every unit but collates nationally mandated key data required for national reporting (NCCMDS,

NNAP, and NDS), as well as providing a clinical record of care during the stay. Data in this system is linked if the baby moves between neonatal units (but is not linked if the baby moves outside of neonatal units, for example to paediatrics or surgery).

51. How data is collected in individual units will vary. and many units are still working with paper-based notes. During 2015-16, in most units, regular observations were still charted on paper by nurses at the bedside and it should be noted that a significant number of neonatal units are still using paper-based notes in 2024. However, all units will be entering key admission and discharge details including data items required on a daily basis to capture the specialised neonatal HRGs (see above) and producing a summary of care record including a discharge summary which can be seen (but not altered) by other neonatal units in the UK if babies are transferred. (This is done on the BadgerNet platform).
52. Some units are able to capture monitoring data and have linkage to equipment (eg ventilator and syringe pumps) and electronic prescribing within a full electronic data capture system. This may be done on a number of different platforms (including BadgerNet) but with key information still moving across to BadgerNet platform to allow monitoring of activity and pathways at a network/commissioner level and to support collection of the data items required for NCCMDS, NDS and NNAP.
53. In 2023, the picture is still very mixed with variable implementation of electronic patient records (EPR) and not all units have introduced EPR systems that pull through vital monitoring signs e.g. Heart rate or respiratory rate electronically. Full electronic patient record systems may be able to capture sudden changes in a baby's heart rate, respiratory rate and/or oxygen levels depending on how they are set up but this would not be collected in the standard BadgerNet summary care record platform used across the country. Some units have data capture and storage of vital signs, (eg. heart rate, respiratory rate, blood pressure, oxygen saturations), for a variable period of time.
54. Serious adverse events are captured through individuals reporting serious adverse events through their local trust reporting mechanisms, and from there, through regional and [national reporting mechanisms](#). Clinical notes recorded by the nursing and medical practitioners would record a summary of the events around a serious

adverse event and there may be documentation of investigations and vital signs if appropriate. However, there is no mechanism for transfer of serious adverse events information for collection nationally through the BadgerNet platform, and therefore no collection of this data in current neonatal national datasets including NNAP, NCCMDS and NDS.

55. BAPM has run a number of working groups concerned with data issues. The BAPM records show that a group met sporadically between 2009 and 2012 to develop recommendations around which data items should be collected and how these were defined. Outputs from these groups were the BAPM Minimum dataset and categories of care documents.

56. In January 2021, BAPM re-convened a Data and Informatics Steering Group with an aim to champion and support perinatal professionals with the use of neonatal data to improve neonatal care and services.

57. The remit of the 2021 steering group is as follows:

- Advocacy for the collection and use of accurate data to benefit patient care and neonatal services.
- Development of shared resources to support perinatal professionals to maximise the utility of data to benefit patient care.
- Promotion of a nationally standardised approach to quality measure definitions and interoperability of EPR systems, reducing the burden of data entry for clinical staff.
- Facilitation of collaborative engagement between stakeholders to streamline data collection, curation and analysis for common purposes.

58. BAPM also runs a data stakeholders' group that brings together a range of organisations with an interest in neonatal data. These organisations meet twice per year to provide updates and share information in regards to neonatal data. There are generally not many actions from this meeting, it is more for information sharing.

59. The membership of the data stakeholders group includes:

- NHS England's Maternity and Neonatal Safety Improvement Programme (MatNeoSIP)

- Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries (MBRRACE-UK)
- National Child Mortality Database (NCMD)
- Neonatal Data Analysis Unit (NDAU)
- National Maternity and Perinatal Audit (NMPA)
- Getting it right First time (GIRFT)
- Neonatal Critical Care Minimum Dataset (NCCMDS)
- Royal College of Paediatrics and Child Health (RCPCH).
- National Neonatal Audit Programme (NNAP).
- England Neonatal Networks
- Welsh Neonatal Network
- Northern Ireland Neonatal Network
- Scottish Neonatal Network
- NHS England – Commissioning
- NHS England – Clinical Reference Group

60. BAPM does not collect or hold any data relating to patient care. The only data we hold is in relation to our members for the purpose of running the organisation and responses to any surveys that we have run to contribute to our frameworks and QI toolkits.

61. BAPM has not undertaken our own reviews in neonatal data but provides an advisory role to the Neonatal Audit Programme (NNAP) as well as Mothers and Babies: Reducing Risk through Audit and Confidential Enquiries (MBRRACE), Neonatal Critical Care Minimum Data Set (NCCMDS), Saving Babies Lives v3 data collection. We also suggest data collection should be happening at a local level through our Quality Standards Documents.

Section 6 - Service Standards

62. BAPM's Service and Quality Standards were published in November 2022 and provides a consensus view of service and quality standards for the provision of neonatal care in the UK. It is the amalgamation of two previously published documents: the BAPM Service Standards (2010) and Neonatal Service Quality Indicators documents (2017). It was developed by a small working group working to

update the two previous documents and was then sent to BAPM members and stakeholders for consultation before a final version was agreed and published.

63. The recommendations in this document represent a professional view of the current best practice principles as they apply to neonatal care and are consistent with the Neonatal Critical Care Review (NCCR). Recognising some differences in the organisation of services between the devolved nations, BAPM Service and Quality Standards are intended to be applicable throughout the UK.
64. The Service and Quality Standards document is not intended to replace any of the national standards and guidelines around neonatal care, but rather to complement them and provide a consensus view of service and quality standards for the provision of neonatal care in the UK. The standards document references other external guidelines and seeks to contextualise these and make it easier for neonatal staff to make sense of the vast number of standards relevant to neonatal care.
65. BAPM does not have the resources or authority to monitor or track adherence to our standards but we do what we can to influence appropriate standards bodies to take note of our recommendations. In 2017 BAPM wrote to NNAP asking that it add a measure on nursing standards to the national audit programme. This was reported from 2018 onwards making it transparent which units met the recommended nursing staff levels.

Section 7 – staffing recommendations and training

BAPM has produced a number of documents that contain staffing recommendations:

- [The BAPM service standards document – Third Edition \(2010\)](#)
- [Optimal Arrangements for Neonatal Intensive Care Units in the UK \(2014\).](#)
- [Categories of Care \(2011\)](#)
- [Optimal arrangements for Local Neonatal Units and Special Care Units in the UK including guidance on their staffing \(2018\)](#)
- [Calculating Unit Cot numbers and Nurse Staffing Establishment and Determining Cot Capacity \(2019\)](#)
- [Optimal Arrangements for Neonatal Intensive Care Units in the UK including guidance on their medical staffing \(2021\)](#)
- [Consultant Working Patterns – a report \(2023\)](#)

66. BAPM is not involved in setting the curriculum or training for those working in neonatal units, this is managed by the Royal Colleges. BAPM has produced an [Advanced Neonatal Nurse Practitioner Capabilities Framework](#) which sets out the capabilities expected at the level of ANNP, Senior ANNP and Consultant Nurse using the four pillars of advanced practice, clinical practice, leadership, education and research. This framework contains recommendations only and is not mandatory for ANNPs to follow.

67. Whilst not being directly involved in training, BAPM provides continuing professional development opportunities for members through the provision of conferences and (since 2020) webinars.

Section 8 – Incidents at Countess of Chester Hospital (CoCH)

68. The BAPM office have checked the BAPM records from 2014-16 and cannot find any evidence of concerns raised about the neonatal unit at CoCH. Dr Alan Fenton, BAPM President 2014-17 confirms that to his knowledge BAPM were not contacted during his time in office. BAPM Office staff have also searched the electronic files and can also find no correspondence to suggest any contact from RCPCH or others regarding concerns at Countess of Chester.

69. Members of BAPM EC may have been aware of press coverage regarding higher death rates and a murder investigation but it would not be normal for excess death rates to be reported to BAPM. We have checked the records of Executive Committee meetings to see if any members have raised a concern about this but we cannot find any record of this being discussed. I had previously been made aware of the case and increased death rates in my role as GIRFT Clinical Lead for Neonatology. I was contacted in my role as BAPM president by Dr Stephen Brearey a few weeks before the criminal trial commenced, and a telephone discussion followed to explain that the case was going to trial.

70. BAPM's National Policy Sub-group has agreed a series of actions following the verdict. This group meeting is usually attended by a sub-section of the BAPM Executive Committee but in order for us to best consider appropriate actions to take in response to the outcomes of the Letby Trial we have invited several other

organisations to send representatives to join us for meetings for the time being.

These are:

- Bliss
- Neonatal Nurses Association
- Neonatal and Paediatric Pharmacy Group.

71. The group have agreed a number of actions appropriate for BAPM to take:

72. **Post-trial Statement:** In September 2023 BAPM published a [statement](#) on our website and social media shortly after the trial verdict.

73. **Insulin letter** – In December 2023 BAPM, Bliss Charity and the NPPG wrote to the Association for Quality Management in Laboratory Medicine (AQMLM) to ask for their support to develop improved standardisation of measurement, reporting and communication of serum insulin and C peptide test results. From the information available in the press regarding this case, results which could have potentially indicated the possibility that insulin had been administered to a baby (rather than being produced by a baby), were not immediately flagged in a timely manner which would alert clinicians to this possibility. Insulin has been used by a previous healthcare professional (Beverly Allitt) to murder children. The group felt that standardising the way insulin is measured, reported and how reporting of results suggesting overdose of insulin is transmitted to health professional would be an important step forward for all patients to ensure safe practice. **EA/2: INQ0012959**

74. **Letter on neonatal expertise of medical examiners:** A small working group comprising representatives from all four UK nations has convened to discuss the current medical examiner and coronial processes and to make suggestions on how these might be improved. It has been agreed to write a letter suggesting the appointment of regional medical examiners with neonatal expertise. (Currently in development.)

75. **Guidance on mortality governance:** BAPM plans to develop a document on neonatal mortality governance and we will invite the chief coroner and Royal College of Pathologists to be part of this working group.

76. **FAQs for health care professionals and parents / carers** (Currently in development)

77. Networks Meeting Session: BAPM ran a session at the BAPM Networks meeting on 17th January 2024 titled 'After the Letby Trial – what has BAPM done and what support do the networks need.' This session updated network representatives about the work that BAPM has done (outlined above) and asked if they felt there was anything else that BAPM should do or could help them to access support from other bodies. Staff reported feeling increasingly challenged and needed more support to share their own experiences and concerns. They are worried that small errors may be overly scrutinised and there were suggestions of additional bureaucracy around death reviews that network staff felt would add to the administrative burden without increasingly the likelihood of recognising anomalies. Attendees called for more standardisation for neonatal reviews from coroners and medical examiners. It was also mentioned that networks found it difficult to get timely data on mortality that would help them recognise anything out of the ordinary quickly.

78. Work with NPPG: BAPM will continue to work with NPPG to improve drug safety in neonates. This includes development of standardised concentrations for infusions (including insulin) in neonates to reduce the risk of error and developing a joint position statement regarding infusion management in neonates (currently in development).

79. Neonatal Safety Champion: BAPM has been calling for the appointment of a National Neonatal Safety Champion for several years now. We will continue this campaign.

EA/3: INQ0012960, EA/4: INQ0012961, EA/5: INQ0012956, EA/6: INQ0012953, EA/7: INQ0012957

Section 9 – Future recommendations

80. With regards to NHS Management structures and processes, BAPM EC fully supports greater managerial accountability for neonatal safety, from ward to board, including greater visibility of neonatal patient safety champions at all levels of the organisational structure.

81. BAPM strongly supports making better use of digital technology. However, we are concerned that there is a lack of focus on digital transformation within neonatology which is a huge omission in the [Single Delivery Report](#). Whilst most neonatal units still use a single neonatal data system for some data collection, there is often no data

linkage between this system and evolving local trust EPR systems. In addition, sometimes neonatal units are required to use a different internal system to their trust maternity EPR with poor system linkage. The lack of understanding regarding neonatal data flows is beginning to cause fractures to the previously high-quality data collection in UK Neonatal units.

EA/8: INQ0012955, EA/9: INQ0012958

- BAPM is conscious of the major benefits that have been accrued through collection of patient data, on every NHS neonatal patient, on a single system over a period of more than ten years. These benefits extend to commissioning, network oversight, audit and research. BAPM's perspective on the move away from written records into various forms of Electronic Patient Records (EPR) is informed by the need to preserve the benefits of existing dataflows, while seeking to adhere to the following principles:
- Data should be entered once, and used for multiple purposes
- Routine data flow to a central repository of neonatal data, accessible to NHS and other appropriate partners
- Vendor neutrality
- Interoperability of data systems
- Minimisation of barriers to data use

82. There are currently a variety of EPR solutions implemented by UK healthcare organisations. These vary from whole organisation 'enterprise EPRs' where a single EPR seeks to address the record keeping needs of all healthcare provision, to different hybrids. In particular, BAPM are conscious of the advantages of maternity data that can flow into neonatal patient records, and the importance therefore of interoperability between a single organisation's maternity and neonatal EPR. Further, being aware that 1 neonatal patient in 7 is transferred between healthcare organisations, there is a need for information to follow the patient transfer across different hospitals without impediment or repeated data entry.

83. BAPM are always mindful of the primary purpose of medical records, which is to record observations, activity and crucially interpretations of healthcare data - typically referred to as diagnoses. EPRs, and the interoperability between EPRs should promote recording of diagnostic data, alongside evidence of how this has been communicated to families.

84. BAPM has developed a toolkit on Implementing a [Neonatal Electronic Health Record](#).

This toolkit was finalised for release on February 14th 2024. This toolkit has been developed in recognition of the increasing implementation of trust-wide electronic patient record (EPR) or electronic health record systems (EHRs), and the growing expectation for the involvement of neonatal health professionals in the selection and implementation of electronic records locally and regionally.

85. Where trust wide EHR systems are implemented, due consideration should be given to the impact on existing data entry and flow and clinical teams should not be expected to duplicate data entry.

86. The document aims to:

- Ensure that neonatology remains an integral part of any hospital wide EPR.
- Equip neonatal teams with the knowledge to enable neonatal teams across the UK to actively engage with their organisation's digital journey leading to digital solutions appropriate and adequate for the needs of staff, babies and their families.
- Provide a list of essential, highly desirable and desirable capabilities defining the neonatal need for record keeping, local and national audit, quality improvement and benchmarking, and research.
- Provide healthcare professionals caring for neonates the understanding and language to discuss their EPR needs with technical and procurement teams from scoping, selection through to implementation.
- Share knowledge and experience from teams that have experienced an EPR configuration and implementation, with teams at different stages of the process.

87. In addition, at neonatal ODN level, there is significant inequality in access to data analysis support and a commitment to support equity of data analytics across all ODNs would allow greater alignment of national data, supporting improved benchmarking and quality improvement work.

88. BAPM recommends that:

- Trusts ensure that maternity and neonatal electronic patient record systems are fully linked to facilitate improved clinical care and avoid duplication of data entry.

- Neonatal services are given focussed support from Trust EPR teams, to understand the needs of the service and the dataflows required.
- Trusts use the BAPM toolkit “Implementing a Neonatal Electronic Health Record” published February 2024, to ensure their neonatal EPR system is fit for purpose.
- Funding is required to support equity of data analytics across all ODNs
- BAPM remains committed to the goal of single data entry with seamless data transfer between maternal and neonatal records, and to national systems used for monitoring patient pathways, activity & acuity, national benchmarking, audit and research.
- Regarding the role of data in safeguarding babies, more timely reporting of mortality and morbidity data may help (NNAP is now reporting rolling quarterly mortality at a network level, as well as key morbidity outcomes) and it is possible that reporting measures currently being developed by the Reading the Signals Group will also allow earlier in-depth review of areas of possible concern. However, the focus on PMRT and morbidity mortality review with independent external review is extremely important. Appropriate time must be allocated into staff job plans to allow independent external reviews to be carried out and properly resourced.

89. Documents to attach:

- Letter to AQMLM
- Letter to NHS England and DHSC re Single Delivery Plan
- Letter re the data issues to NHS England
- Letters in regards to Neonatal Safety Champion x5
- Data Landscape journal article

Statement of Truth

90. 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: 15th February 2024