Name	Comments	Working group response
Tom McEwan Individual	**Any other comments** Overall this appears to be a well constructed, comprehensive and clear framework that, if implemented, should have a positive impact on the experience of families and staff providing care. A very minor point is that ODN's are referenced throughout which are not a feature in Scotland, so it may be helpful to acknowledge this somewhere in the document. We currently have the Scottish Perinatal Network, which features both neonatal and maternity networks, and whilst there are some similarities to ODNs they are not the same at present. It is important to note the strategic networks in Scotland are currently the subject of a service review. Great work by all involved.	Thank you for your kind comments. We have changed reference to neonatal ODNs to neonatal ODNs/Perinatal Networks to reflect the differences in Scotland and Wales which include maternity.
Nicola Medd Individual	**Care of Baby and Family** I like the section on involvement of family esp involvement in CDRM questions. In our region we get some push back from some organisatons and clinicians that the time to see families isnt job planned, other organisations just do it as good practice. It might be worth including something around feeding back post mortem results to family as that is also something we occ struggle to get organisations to do. They need someone (ideally a senior clinician) who will meet up with families, go through post mortem, decide if there are any other tests required as a result, e.g. genetic family testing and feed this into the review processes.	Good point re later feedback. The following is now included in the Family support and communication section • "The named consultant should offer families the opportunity to meet to discuss o the results of the postmortem, and any outstanding investigations o the outcome and any actions following the CDRM o the outcome and any actions following any internal or external investigations "

	Child Death Review - Immediate Decisions The sudden unexpected death section is interesting. Hopefully you will know from your ARCDP rep on the team that we had a seminar on this issue at the last national conference. It is quite controversial and not clear and I feel you will need further clarification here to help teams and designated doctors know what to do. The problem is that occasionally babies die on neonatal units suddenly and unexpectedly from sepsis or other medical issues which come on quickly. In some the cause of death isn't known by medical professionals so a coronial referral or PME may be needed but it will a medical cause of death. The JAR process was initially set up for the SIDS cases and over time has been extrapolated without national guidance into all sorts of deaths. In a large proportion of cases the JAR clinician will be not neonatally trained and infact the neonatal team will be the best people to advise on concerns in a multiagency forum. You also have the problem that at present the JAR teams work on address (postcode of where parents live) but a baby may die on a NICU many miles away from there. There is no clarity about which team should do the JAR - which police? which paediatrician? Are they expected to travel to the NICU to see the place of collapse. There is definitely a role for a JAR on a NICU (we indeed have had SIDS on NICU's) but it requires a lot more thinking through and guidance as otherwise it will be interpreted inappropriately. With the Letby case teams will be worried about police presence on NICU's and I am not sure police will know what they are doing. Whether a 'modified JAR' is the way forward with multiagency discussion but not	We agree that this can be a difficult area for neonatal cases and hope we have provided examples of when a JAR/PRUDiC or equivalent should be considered. This list is not exhaustive but provides some structure for consistency. We suggest that you contact the designated doctor if there is uncertainty about how to proceed regarding the logistics of the multiagency response. Your comments on guidance for JAR in cases from neonatal unit will be passed on to the national group looking at reviewing the statutory CDR guidance in England. Your comments will be passed on to the national group looking at reviewing the statutory CDR guidance in England.

	everyone coming onto NICU's is something to consider but a larger piece of work I think?	
	Child Death Review - Child Death Review Meeting I just wonder whether you could clarify what form of review would be appropriate for <22 week gestation babies. We are getting at our CDOP increasing numbers of babies born with signs of life at gestations as low as 18 weeks. Generally they get no internal Trust based review until they come to CDOP where the learning is quite limited. A few Trusts have done special reviews just to highlight learning points but I just wonder whether you could clarify any national expectations (or none) of review at these previable gestations.	We have tried to be as specific as possible regarding the CDRM- "The review processes for deaths of live births should chiefly focus on babies who are born on or after 22+0 weeks gestation but should also include more immature babies if active resuscitation is undertaken. " The statutory review process in England includes all live-births so will include those born below the limits of viability. We will pass on your comments regarding expectations for CDOPs for review of babies below limit of viability on to the national group looking at reviewing the statutory CDR guidance in England.
	Reporting, Review and Dissemination of Learning Just to say in figure 1 (page 22) as a CDOP we would also ask for assurance from organisations if appropriate. We do this if their PSRF action plan has been inacted or if there are service issues that require resolution. We dont do it in all case reviews we do but will write to organisations etc if required. At CDOP we also have public health colleagues so examples of our dissemination of learning has been our recent Neonatal CDOP report being used to influence a public health project on reducing infant mortality. It can liaise with other public health workstreams such as smoking cessation and maternal obesity services. So I know you mention commissioners as providing assurance etc but I think CDOP also do this.	Thank you for the information and it is great to hear how the themes and data from your CDOP reports have influenced practice. The figure currently includes CDOP reports in the regional reporting outputs structure and NCMD in the national reporting outputs. We have added CDOPs to the assurance section of the figure.

	Thematic learning is also captured at a national level by the NCMD who from time to time produce thematic reports with a neonatal focus. The advantage of this is the large numbers etc. I guess it is just important to acknowledge that all these different processes have a slightly different footprint and so may have slightly different cases - CDOPs work on postcode of parents, Trust based reviews incl PMRT work on place of care antenatally and postnatally and these may be different. Different mortality based rates have different denominators etc causing different mortality rates. Some are if you die only before 28 days, some only if you die on NICUS (would capture SIDS deaths after discharge in preterm babies for example or babies transferred to PICU / surgical centres).	
	Staff Considerations Good to have the time required incl in job planning and nursing time.	Thank you
	Appendix 3 – Case Examples Unattended stillbirth after 24 weeks - the way this is written is a bit confusing. At the top you are saying it is a stillbirth (although unattended) quite quickly and doesn't need referral to coroner etc but at the same time lower down you say it needs a JAR? This doesn't really work in practice as police wont get involved if not a coroners case and if signed off as a stillbirth they wont want to do a JAR. This is a very contraversial area - we have just written a detailed guideline on it for our area - and our view is that you don't really know if it is a stillbirth or not because no medical professional was in attendance. If the baby is	Thank you for these comments. Case 3 has been modified slightly and now reads: "A MCCD cannot be issued. A JAR/PRUDIC or equivalent should take place where there is uncertainty regarding whether the baby is live-born. If the baby is determined to be stillborn a medical certificate of stillbirth can be issued, and the birth must legally be registered as a stillbirth." Changes to the discussion points include: • "It is common that it is not possible to determine whether the baby was alive or stillborn. Where there is uncertainty regarding whether the baby was live-born or not, no MCCD should be

	macerated then you can but in most other situations you cant. Our local guidance is to refer all to coroner, do a JAR and CDOP notification and then step down if it becomes apparent that it was a stillbirth but it is is contraversial area and we could do with a better national guidance on what to do as everyone does it slightly differently region to region. Unexpected collapse in a ventilated baby - I don't think in the example you gave a JAR is indicated. This isnt the purpose of a JAR. I am not sure what it would achieve and will be highly controversial - I think this needs more thought and guidance as stated above in my section on this earlier with all the challenges I have already mentioned about the experience of the JAR doctor or nurse, which JAR team is going to do this (esp with most of these happening in tertiary units), what is it we are looking for (if we are worried about criminal or non natural causes of death we have other systems for investigating this and infact a JAR is not an appropriate tool to investigate potential criminal behaviour). I think a better case for a JAR would be a baby in the special care area - corrected to 35 weeks and now not monitored - is found dead in the cot in the morning. The sepsis baby may or may not be considered for a JAR but might depend on more details.	issued, a referral to HMC/PF should take place and, in England, the case should be referred to CDOP. • The CDOP process would not be continued if it is determined that a baby was stillborn and the case records should be deleted." This case has been modified slightly to read: "A JAR/ PRUDiC referral or equivalent should be considered if the death is sudden with no immediate apparent medical cause."
	Any other comments A helpful guideline which will help organisations prioritise child death review . However I do feel the controversial areas around JAR on a NICU need further explanation / guidance, as given the detailed discussions held at the seminar last year at the ARCDP	JAR in NICU - We agree that this can be a difficult area for neonatal cases and hope we have provided examples of when a JAR/PRUDiC or equivalent should be considered. This list is not exhaustive but provides some structure for consistency.

	conference these will be very controversial and not straight forward to implement. My general feeling also is that PMRT is quite a crude mortality tool and misses on on a more holistic review that is covered in a CDRM. Whilst we cant create more work for organisations, and using the PMRT tool for mortality review seems fair, it seems a shame to me that we miss out often on the depth of other information which comes out of a more detailed holistic review. The PMRT is very medically focussed and misses out on many other determinants of health such as deprivation etc and capturing this data is important in understanding why babies die and what we can do about reducing those deaths moving forwards. getting organisations and clinicians to look at the bigger picture is important I feel. My background is as a general and LNU neonatal consultant and as a designated doctor for child death.	The purpose of PMRT is to improve the quality of reviews and to standardise the way they are done. The current statutory guidance suggests that PMRT be used to review deaths of babies in a midwifery unit, on delivery suite, and in a neonatal intensive care unit. In situations where a JAR is conducted, we would expect the health professional leading the JAR to convene a CDRM - PMRT may not be used in this context. You are right that PMRT is very medically focused and often when a JAR is conducted there are other elements for discussion that are not the focus of the questions in PMRT. It would then be the responsibility of the CDOP review to assess whether the PMRT review had considered the wider social determinants and, if they had not been considered, that CDOP themselves record them in the final analysis form which goes through to NCMD to ensure those elements are captured for national analysis. Your comments on guidance for JAR in cases from neonatal unit and more clarity regarding the interface between PMRT and CDRM will be passed on to the national group looking at reviewing the statutory CDR guidance in England.
Lisa Leppard Individual	**Executive Summary** I am disappointed that there are not more nursing and palliative care voices on the working group. Some abbreviations are missing. SUDIC. PRUDIC.SUPC in index Recommendations should include milk donation with organ donation	There was representation from many different groups on this document and nursing and bereavement were included within this. We are sorry that a specific palliative care voice was not on the group but we have incorporated feedback from this area.

	Should there a recommendations around staff education and training. I am not sure this is always seen as a priority for some unit managers.	SUDIC, PRUDIC, SUPC are all included in the abbreviations table. Milk donation is included in the care of the family and baby section and we have increased the information around lactation after loss. We have included training requirements in "staff considerations" and "supporting families and staff" appendix as well as including suggested staffing time for bereavement and mortality governance.
	Introduction/Care of Baby and Family (same comment under both) When a baby dies in a hospice setting, the Key Nurse (in England) must be allocated from the Units the baby was transferred from. I think this needs clarifying in this document as I am aware that this is variable and is often an expectation of the hospice. It should be the neonatal unit, as they will be following the family up and with and be in contact with the Coroner or Pathologist when a PM is undertaken.	We have added in the following to the care of baby/family • Where possible, families should be given options for where end of life care takes place, including hospice and home care, or transfer to a hospital nearer their home e.g. local LNU/SCU. In such cases, there should be clarification regarding the named consultant and key worker prior to transfer.
	Child Death Review - Immediate Decisions Pg12. P1. should it be 'will' not 'may' help with decision making. This has to be discusses with the ME. pG12. P5. 'In E&W proposed MCCD will be scrutinised by ME' This is repeated again in ME section . Does this need to be in 2 places? Registration. Pg 15. point 4 'Registered within 5 days E&W' Should this read 5 working days?	We have adjusted this to read • In England and Wales, the proposed MCCD/case will then be scrutinised by a Medical Examiner (ME), with correspondence or verbal discussion between the ME and the attending physician. We have left both in as one describes the flow process and the other is more specific information on the role of the ME Working days added to document- thank you

	Child Death Review - Child Death Review Meeting Representation at CDRM should be open to all staff on the neonatal unit who were involved in the care of the baby and family, to be able to be involved in discussions and sharing their thoughts in a supported, non judgemental environment.	We have added this point into the text. • Representation at CDRM should include all staff who participated in the baby's care and the meeting should be open to all perinatal staff. All staff should feel able to contribute in a supported, non-judgemental environment.
	Staff Considerations Pleased to see the BAPM staffing recommendations highlighted again in this document 1x WTE Band 7 Neonatal Nurse minimum for NICU's, this does not have to be a bereavement midwife and should be an experienced neonatal nurse. All networks should have allocated time for lead mortality governance roles for both medical (minimum 1PA) and nursing (minimum 0.1WTE) staff to allow review of learning from neonatal network deaths, thematic review, network actions and QI and national benchmarking and assurance. Really important to have the nursing voice in these reviews. I'm really please to see this highlighted	The information included matches the information in appendix E of the palliative care document. We have included neonatal nurse in to make it clearer. Thank you for your positive comments on nursing voices in the reviews.
	Appendix 1 – Supporting Families and Staff This Appendix 1 is very long could it have an index on contents. Will help users find the content they might be searching for. Its 13 pages long.	We have separated out Appendix 1, 2 and 3 from the main document and put an index for each to make it easier for people to read separately.
	Appendix 2 – National Guidance	

	I like a flow chart these are useful HMC notification very helpful for clarity for teams , even thought this process would be discussed with the ME now , so the onus is not one clinicians to make that decision.	Thank you
	Appendix 3 – Case Examples Case examples ae always helpful for insight. Again an index of these cases might be helpful to guide the reader to the example they might be looking for , rather than searching through all the cases.	Separated out with their own index – thank you.
	Any other comments This is a huge document. Perhaps a more detailed index would help as, there are huge amounts of information under each heading as indexed currently.	Thank you – now separated out
Karen Turnock Individual	**Executive Summary** There is a statement that all neonatal units should use the PMRT for all neonatal deaths regardless of the location of death but if the death is in PICU or other children's services what is the expectation?	This has been clarified in the executive summary to: • All neonatal units should use the Perinatal Mortality Review Tool (PMRT) to support the child death review meeting (CDRM) for all neonatal deaths in the first 28 days when neonatal care has been received, regardless of the location of death (can also be used for babies who die in neonatal units after 28 days). Main CDRM section, clarification regarding when neonatal care has not taken place and death occurs elsewhere: • Across the UK, the PMRT process should be used for all neonatal deaths in the first 28 days when neonatal care has

		been received, regardless of where the patient dies. For deaths in other locations in the first 28 days, when neonatal care has not taken place, e.g. Paediatric Critical Care, consider use of PMRT and if this is not possible, careful consideration of perinatal factors should be incorporated into the CDRM and CDOP (Eng) reviews, and the PMRT should be closed.
	Introduction The statistics in the first paragraph are really difficult to understand - 52% of deaths below age 16 are neonatal and 40% below 18 in maternity and neonatal services? What is this supposed to tell us? I think it would be more useful to have the same denominator (all child deaths before age 18 as those are the NCMD population??) and express the percentage of neonatal deaths in perinatal services and the percentage of all deaths in perinatal services - be good to have the percentage of neonatal deaths that do NOT occur in perinatal services. By perinatal I mean maternity units and neonatal units including direct transfers from neonatal units for end of life care in home or hospice setting.	We feel the current data gives a good overview of the different ways of looking at neonatal deaths ONS data is for <16. We include ONS, MBRRACE and NCMD data as all are relevant and have a slightly different perspective. All demonstrate neonatal death being significant. We have updated reference 1 and 2 to reflect the most recent data
	Child Death Review - Immediate Decisions You are promoting three regional review processes - very saddened that this is not suggesting a single regional review process and we are still lumbered with providing multiple outputs. The role of the medical examiner in exploring the need for Coronial referral is inadequately explored - it suggests these are	We do not think that we are promoting three regional review process but the organisations do need ot work together. We have suggested in the text that CDOP processes should not be repeated in ODN review. The ODN and LMNS should be working in partnership, and we have written this into the document in the reporting and review section. • The regional ODN/Perinatal Network footprint provides a better platform for collating themes and shared learning. Regional

	separate but MEs are ideally placed to support clinical teams with this decision making - the narrative contradicts the boxed information on the role of the medical examiner	review should not repeat the local CDRM process. Thematic review across CDOP, ODN/Perinatal regional networks, LMNS and other regional processes should be co-ordinated. Sharing of information between these groups is strongly encouraged to ensure a joined-up approach.
	Child Death Review - Child Death Review Meeting Very disappointed that there is a suggestion to divide the PMRT from the CDR 'if postnatal care has been prolonged or complex' - this is the model many units have taken to avoid the tedium of the box ticking in the PMRT and to hold a proper CDR, where we should be insisting on better tools - the PMRT is an agnostic tool for loss after 'normal' pregnancy. We know the most common causes of neonatal deaths are related to prematurity and congenital anomalies - the PMRT provides a woefully inadequate review of preterm prediction, prevention, and optimisation and pays scant attention to pathways of care for anomalies. It is deeply frustrating that we are not learning from what we know and developing our reviews appropriately but instead being diverted by the concepts of multiple regional reviews and even worse 'external reviewers' in local review meetings - these should surely be in the robust regional review (they are not mentioned in the statutory guidance for CDR). Every team is different but question the contradiction of psychological safety for a team to review and critically evaluate care with independent external reviewers there to call the team to account. The conversation becomes restricted and constrained. What is the evidence that this helps anything?	We stand by our current text regarding the PMRT which is a thorough standardised tool for perinatal death. Our point regarding additional CDR is to allow flexibility in the approach taken, particularly when the patient has had a complex postnatal course. The practicalities of how this is achieved will be down to local units to determine. We do feel that PMRT supports learning in preterm and congenital anomaly related reviews and provides opportunities to identify local and regional learning with recorded actions to improve things at these levels. The CDOP review provides a further layer of independent scrutiny of the learning and identified actions. Regional reviews should not repeat local processes. See in previous comment which has been expanded. External reviewers provide a key independent perspective and indeed permit sharing of best practice. There is a strong call from families for external review. Feedback from within the working group suggested this was beneficial.

	Reporting, Review and Dissemination of Learning Learning needs to be challenged and shared at regional level, so we need single thematic forums; most of what we learn is systems based but also lack of evidence - how do you balance non-intervention in extreme premature labour with getting babies out in better condition? So there is a strong argument for a detailed consideration of what we learn from extreme preterm deaths (including those beyond the neonatal period); but also things like supra-regional review of congenital anomaly deaths with fetal medicine leads and commissioners...	We agree with your sentiments and ODN and LMNS parts of the system can co-operate to facilitate this kind of discussion. We have expanded on the following bullet point as outlined above to read: • The regional ODN/Perinatal Network footprint provides a better platform for collating themes and shared learning. Regional level review should not repeat the local CDRM processes. Thematic review across CDOP, ODN/Perinatal regional networks, LMNS and other regional processes should be co-ordinated. Sharing of information between these groups is strongly encouraged to ensure a joined up approach.
	Staff Considerations Real world view would be appreciated instead of making everyone feel like this is something new and needing a fortune spent on it. Mortality review and parental support after bereavement is a core activity - maybe improve and streamline the documentation, insist on reporting tools that work - the reporting forms are random in structure and content and often required in addition to the PMRT, and if we don't have enough time to hold reviews in our own Units who is providing the multiple layers of external reviewer for complex cases? We have a small amount of very welcome ODN funding to attend reviews when babies die in our LNUs - these are often babies we have known about so would not be considered independent but we feel it is important to be part of those reviews as deaths in LNU (we have no network SCU) are not typical.	We agree that mortality review and parental support are part of everyone's workload, but they should be included as part of job plans. Different trusts have different rules for what is counted as part of core activities and SPA allocation is highly variable. This is why we have worded the job plan section in the way we have. We would strongly agree that all people involved in the care should try to attend the CDRM.
	Appendix 1 – Supporting Families and Staff	

	Doesn't match the earlier descriptions. We are fortunate in having a committed and experienced team of keyworkers who understand the different ways families need to be supported through the review meeting and what feedback they want- the structure may be useful if you undertake a couple of reviews a year and need additional support but we need to accept that all families grieve differently, many have no unanswered questions - so not all want to fill in a form and have a written letter.	Appendix 1 is consistent with the main document but provides complementary and more detailed information for family support. We agree that a flexible approach to support family's needs is required.
	Appendix 2 – National Guidance I can't see the national Coronial guidance that live birth after termination needs Coronial referral?	This is correct and reference is made to Chief Coroner's Guidance no. 45
	Any other comments I really think we should be fighting for better structures for reviews for neonatal deaths, and single structure of regional reviews with focus on thematic questions we can't answer and systems learning accepting these do not map to LMNS or ODN structures	Your comments will be passed on to the national group looking at reviewing the statutory CDR guidance in England.
Dr Lydia Bowden On behalf of Oldham Care organisation NCA, GM paediatric palliative care network	**Executive Summary** Good summary	Thank you for your comments.
	Care of Baby and Family Comprehensive guide to caring for family including the NBCP standards	Thank you for your comments.

	Child Death Review - Immediate Decisions Import summary of numerous statutory reporting and referrals. Important that links between primary and secondary care as Mbrrace surveillance and pmrt notification will still need to be done if baby has had care on Neonatal unit , and there is a tight deadline for completion	Thank you for your comments.
	Child Death Review - Child Death Review Meeting Need to ensure obstetric involvement in medical examiner scrutiny and referral especially if maternal cause on death certificate and availability of maternal notes or obstetric consultant to discuss	The working group does not consider obstetric involvement to normally be required. The medical examiners regulations 2024 dictate the roles and responsibilities of the ME (Eng & Wales).
	Reporting, Review and Dissemination of Learning See above. Also shared this document with Medical Examiner colleagues, the majority of whom are not paediatric. Or Neonatal trained, as this is a very comprehensive document, and the examples are very helpful.	Thank you for your comments.
	Staff Considerations Part of NBCP and reviews are very time consuming when done properly. All staff need to have appropriate time in job plan to achieve this. Also appropriate availability of support especially if progress to legal and coronial review.	Agree – The following point has been added to the staffing to support bereavement section: • All staff involved in bereavement care should have appropriate time allocated for undertaking NBCP activities and training.
	Appendix 2 – National Guidance Tables are good summary	Thank you for your comments.
	Appendix 3 – Case Examples	Thank you for your comments.

	Good examples especially for ME colleagues and others who may need to help jnterpret Complex situations	
	Any other comments We have agreed as a perinatal team to adopt this as our governance document when the final version is published as everything is very helpfully contained with in one document. Well done to the advisory team and working party!	Thank you for your comments.
Sabita Uthaya Individual	**Care of Baby and Family** It would be worth highlighting that if organ donation (for eg heart valves that is time-critical) is being considered in addition to a post mortem examination, coordination between the organ retrieval team and the perinatal pathologist can avoid two procedures being carried out. There is no mention of placental examination and this is key to a full post mortem examination.	Thank you we have added to the organ donation section "Where a postmortem is also being undertaken, co-ordination between organ retrieval teams and the perinatal pathologist will streamline the process." We have added the following to the postmortem section "Examination of the placenta and placental histology can provide important insights into the neonatal death and should be sent, with detailed clinical information, according to national guidelines. Placental histology and postmortem findings should be considered and interpreted together"
	Child Death Review - Child Death Review Meeting Where there is mention of all healthcare professionals being given the opportunity to participate in neonatal mortality governance it would be helpful to state that this should include resident doctors. In many units they are excluded from the PMRT meeting.	We have not specifically mentioned resident doctors as there are many groups who should be included. We have included the following to encompass all staff groups • Representation at CDRM should include all staff who participated in the baby's care and the meeting should be open to all perinatal staff. All staff should feel able to contribute in a supported, non-judgemental environment.

	Reporting, Review and Dissemination of Learning One issue with multiple reports of reviews for eg PMRT and MNSI and a coronial inquest is that sometimes they can vary in their conclusions and this can be confusing for the family. The reports themselves are fed back to the family by different individuals at different time points. Ideally the named consultant should arrange to see the parents once all reports have been completed to answer any questions and address any potential confusion that may arise.	We have included an additional point in the family support and communication section to cover this • "The named consultant should offer families the opportunity to meet to discuss o the results of the postmortem, and any outstanding investigations o the outcome and any actions following the CDRM o the outcome and any actions following any internal or external investigations
	Appendix 3 – Case Examples Table 1 is a repetition of Appendix 2.	We realised this but thought it easier to leave the table in both places as these may be used separately and for ease of reading in appendix 3
	Any other comments Congratulations on a really great piece of work. It is well written and comprehensive. There is a lot of variation in coronial processes between areas. Some work to harmonise processes would be welcome.	Thank you for your comments.
Helen Sullivan On behalf of Perinatal Mortality Review Meeting Royal Wolverhampton NHS Trust	**Any other comments** We have had concerns about the treatment that some of our families experience after the deaths of their babies in perinatal care, when the SUDI protocol is instigated and a quite vigorous police investigations of the family home took place. We felt these parents had been poorly served by the process they were put through. I do appreciate there may be information that can be gained which may be useful to other parents, however I think	Thank you for your comments. We hope that the recommendations here for when a JAR may be appropriate will help to improve matters. Your comments will be passed on to the national group looking at reviewing the statutory CDR guidance in England.

	the benefits of such information have to be weighed against the distress this causes to families at what is such a tragic time in their life particularly when there is an incredibly low likelihood of malevolent action by anybody in the family. I hope this is something that will perhaps be taken into consideration when reviewing the processes and advice for our police services.	
Nanisa Feilden On behalf of Healthcare Improvement Scotland	**Introduction** Page 8, Table 1, Statutory/National Safety Notifications column, last row - HIS National Hub (Scot) The National Hub is jointly run by Healthcare Improvement Scotland and the Care Inspectorate. Conventionally we just refer to the National Hub in publications. Could this be changed to either HIS/CI National Hub (Scot) or just National Hub (Scot)	Changed to National Hub (Scot)
	Child Death Review - Immediate Decisions Page 11, Table 2, CRD Process column, last row - HIS National Hub(Scotland) As noted previously, could this be changed to either HIS/CI National Hub (Scot) or just National Hub (Scot)	Changed to National Hub (Scot) Thank you for picking this up. We have checked this and have removed this sentence.

	Page 15, Registering the death, Bullet point 6 - In Scotland, only the mother can register the death if the parent(s) are not married. My colleagues in DCRS think this sentence is incorrect as applied to Scotland. Could this be checked please?	
	Child Death Review - Child Death Review Meeting Page 18, Child Death Review Meeting Process, second last bulletpoint - The PMRT should be completed at the CDRM. In England, the CDR draft analysis form also needs to be completed and submitted to the Child Death Overview Panel (CDOP) for final independent multi-agency review. Could we suggest the following sentence is added to this paragraph please? In Scotland, the CDR Core dataset should also be completed at the CDRM.	Thank you – this has been added.
	Reporting, Review and Dissemination of Learning Page 22, Fig 1, Disseminating Learning heading, National text box (green) Could we suggest the following mechanism is added to this box for Scotland please? Learning Summaries (Scot)	Added – thank you
	Appendix 2 – National Guidance	

	Page 43, Scotland column, Child Death Review Guidance row - HIS National Guidance when a child or young person dies Please amend to - National Guidance when a child or young person dies Page 43, Scotland column, Medical Death Certificate row My colleagues in DCRS suggest it would be useful to add this link - A Guide to Death Certification Review in Scotland https://eur01.safelinks.protection.outlook.com/?url=https%3A%2F%2Fwww.healthcareimprovementscotland.scot%2Fwp-content%2Fuploads%2F2024%2F07%2FDCRS_Guide_to_Death_Certification_Review_Scotland_June_2022.pdf&data=05%7C02%7Cnanisa.feilden%40nhs.scot%7Cbc6d1181a340411524c308dde960d365%7C10efe0bda0304bca809cb5e6745e499a%7C0%7C0%7C638923324270021761%7CUnknown%7CTWFpbGZsb3d8eyJFbXB0eU1hcGkiOnRydWUsIlYiOiIwLjAuMDAwMCIsIlAiOiJXaW4zMiIsIkFOIjoiTWFpbCIsIldUIjoyfQ%3D%3D%7C0%7C%7C%7C&sdata=lKc4%2FtmwhPe1h7n7i%2F4zWXzfEXW33CKgztBwWLYitCs%3D&reserved=0 Page 50, References, Ref 3 Health Improvement Scotland Please amend to - Healthcare Improvement Scotland HIS National Guidance when a child or young person dies	Added thank you These have been changed.

	As this is a joint programme, please amend to - National Guidance when a child or young person dies	
	Any other comments Page 26, References, Ref 23 Health Improvement Scotland Please amend to - Healthcare Improvement Scotland HIS National Guidance when a child or young person dies As this is a joint programme, please amend to - National Guidance when a child or young person dies General Comment - the National Hub team found this a really clear well written document and would compliment the authors on a great piece of work.	This has been changed Thank you for your kind comments.
Rebekka Jones Individual	**Introduction** Table 1. - Consent for neonatal OD is usually taken prior to the baby's death as neonatal OD usually follows a DCD (donation after circulatory death) pathway. Consent after death may only taken for DBD (donation after death by neurological criteria which is extremely rare for neonatal donations) or for tissue donation. - Completion of CDRM and PMRT by 3 months is very difficult to achieve - 6 months may be more feasible	Thank you. Adjustments made to Table 1 accordingly. We make accommodation for the fact this will be longer if PM/HMC/PF or MNSI so we think within 3 months should be possible for the other deaths.
	Care of Baby and Family	

	Organ donation: Please consider including 4 SNOD notification criteria. These are: 1)Death is likely in the next 48 hours – either by neurological determination of death through testing criteria or by withdrawal of life sustaining treatment 2)Family have raised organ donation 3)Discussions regarding re-orientation of care – including palliative care discussions 4) Early end of life care planning (Reference:https://nhsbtdbe.blob.core.windows.net/umbraco-assets-corp/33479/sop5874-may-24.pdf; Page 23)	Not included as considered too much detail for this guidance. We encourage all units to develop their own guidance with SNOD teams as some would like a lower threshold for contact than described here and to check the baby is eligible before discussing with families.
	Child Death Review - Immediate Decisions Death verification: Please consider expanding guidance to outline appropriate death verification as per most recent code of practice (https://www.aomrc.org.uk/wp-content/uploads/2025/01/Code_of_Practice_Diagnosis_of_Death_010125.pdf). Locally we have found that death verification by cardiovascular criteria is frequently inadequately documented (Page 19 of referenced document). Page 16. Rapid release. I believe the statement regarding OD is incorrect - although for HMC/PF no formal decision can be made until the death has occurred. The OD teams have good working relationships with coroners and will discuss any potential cases for OD with the coroner prior to death. The coroner then advises whether OD (with or without restrictions) can proceed or not.	We have changed the wording of the point around death criteria to make this clearer. Local units can provide more detailed guidance as required. The working group coronial representative advised that this point should written in this way as the coroner has no legal jurisdiction until after death.

	Child Death Review - Child Death Review Meeting ME/HMC: Locally we have encountered issues with accepting of MCCDs in cases of indeterminate gender (usually extreme preterms who have died soon after birth). Guidance regarding such cases to be included may be helpful.	The working group does not consider that this is needed in this guidance. The sex is not a requirement for the MCCD.
	Appendix 2 – National Guidance As above. Difficult to achieve completion of local reviews incl. PMRT within 3 months.	We make accommodation for the fact this will be longer if PM/HMC/PF or MNSI so we think within 3 months should be possible for the other deaths.
	Any other comments Overall, an excellent document!	Thank you for your kind comments.
Sonia Macleod On behalf of Sands	**Introduction** Please could you make the following amendments:- Table 1 add into the Staff Actions/Local Investigations x 1-2 working days box A digital/EPR Flag put onto records	We have added “Digital/EPR flag to notify bereavement on maternal record.
	Care of Baby and Family	

	In the Family Decisions around the time of death (pg 9) add two new bullet point after 'All units should have access to suitable bereavement facilities...' - When there are indications that the environment affected the provision of care HBNs and local SOPs should be reviewed in the CDRM. A remedial plan with milestones should be developed, incorporating family feedback. Action logs should evidence that these are being addressed. (Ref NBCP Standard 2) - Gaps in the Estates provision should be recorded in maternity/Neonatal risk registers and escalated to Trust governance. This provides visibility on their status in ODN assurance assessments. (Ref NBCP Standards 1 and 3)	We have included the following sentence both in the executive summary and in the Care of baby and family section to highlight the NBCP. We have not included all the details in this document: "All units should use the relevant country's National Bereavement Care Pathway (NBCP) for pregnancy and baby loss to guide provision of high-quality compassionate care to bereaved families (ref). The NBCP for England is included in NHS England's medium term planning framework (ref) "
	In the Family Support and Communication section (pg 10) add in a reference to the NBCP Standards 1 and 6 after the bullet point 'All families should have a named lead consultant and a named keyworker (statutory in England)... After the bullet point that starts 'All families should be offered the opportunity to discuss the wording of the Medical Certificate of Cause of Death (MCCD)...' add in two new bullet points - A Documented Personalised Bereavement Care Plan should be created. This forms the record that is referenced in Medical Examiner discussions and submitted to the CDRM/PMRT, (NBCP Standard 1). - The Bereavement care plan should document memory making offers, and cultural/spiritual practices which matter to the family, including rapid release. Audits should be carried out of	Added We have not specifically included this point. We have included more information on this in appendix 1.

	offers accepted and declined and qualitative feedback to evaluate the family support offered and propose corrective actions when needed. (NCBP Standard 3)	
	Child Death Review - Immediate Decisions Child Death Review section (page 11 onwards) Table 2 - After 'Local CDRM' please add (PMRT based) After the bullet point 'All units should use bereavement checklists to ensure timely completion of all appropriate tasks, and these should be made available...' please add a new bullet point -To aid timeliness CDRM tasks should be initiated promptly (do not wait for all externals) The final synthesis only occurs after external reviews (coroner, MNSI, etc) are complete (NBCP Standard 6) In the 'other notifications section' (page 16) please add a bullet point in - A digital/EPR flag is put on the parents' records signifying the bereavement	Leaving as CDRM - we have explained what we mean by this in the document. We have added in “Awaiting results of external reviews should not prevent timely initiation of other CDRM tasks.” Parents or mothers record – won’t usually have a paternal record. Have added – “Maternal hospital notes: place a digital/EPR flag to signify the bereavement”
	Child Death Review - Child Death Review Meeting In the Child Death Review Process section (pg 17 onwards) please put a new bullet point after the 'The Child death review meeting (CDRM) in neonatal practice is predominantly conducted using the PMRT...'	This is already included in the family section

	- To ensure continuity across different reviews a Named Consultant and Named Keyworker should be allocated to families. This is a statutory requirement in England. On page 18 please add a reference to NBCP Standard 1 after the bullet point that starts 'Questions should be submitted by families via the keyworker and/or lead consultant. The CDRM should ensure family views are included, and their questions answered. Parent engagement materials are included on the PMRT website.	Not included here. NBCP reference added prominently in family section.
	Reporting, Review and Dissemination of Learning In the Assurance Section (page 20) please add a new bullet point after the first one - There should be Board level examination of key metrics including:- % families with named keyworker and care plan; % families asked to and engaging with the PMRT (including questions and responses); complaint themes trended via CDOP/NCMD feeds (NBCP Standards 1 & 2) Please add into the final bullet point on page 20 which starts 'Neonatal ODNs should provide quality assurance around the CDRM process.... as follows - Neonatal ODNs should provide quality assurance around their CDRM processes, including reviewing representation at CDRMs, PMRT completion intervals, appropriate family input and response to their questions, PMRT outcome gradings and learning outputs, action plan closure rates, dissemination activities such as logs/newsletters/huddles and thematic outputs from CDOP/NCMD. Neonatal units should provide	We have included the following regarding board oversight: • There should be hospital board-level oversight of key perinatal mortality, morbidity and operational metrics. A national dashboard is being developed to support this in England. Action plan closures added to Neonatal ODN quality assurance. Dissemination activities are described in the Dissemination of learning section.

	ODNS with the information required to facilitate the dissemination of local/regional learnings. (NCBP Standard 6)	
	Staff Considerations In the Dedicated time to support mortality governance processes within neonatology (page 23) please change the first bullet point to - Each unit should have a dedicated consultant and senior nurse for mortality governance with dedicated time to lead/attend neonatal Child Death Reviews, produce reports (including thematic reviews), meet families, attend CDOPs and for dissemination of learning and assurance processes.	We have included attendance at the CDOP in the lead mortality governance roles. Meeting with families is the responsibility of the lead consultant.
	Appendix 1 – Supporting Families and Staff In the Collaboration and Empowerment section on page 32 please add a reference to the NBCP Standard 1 to the first bullet point that begins ' All families should have a lead consultant and a named keyworker....	Added.
	In the Cultural and Spiritual Sensitivity section on page 34 is the inset paragraph a quote from the Lullaby Trust? If not then please can you amend the first paragraph to It is paramount to ask all families what their particular preferences and needs are for all stages of the mortality governance process, and not to make assumptions that parents have specific wishes based on their cultural or religious backgrounds. This should be particularly born in mind when	This is not a quote from the Lullaby Trust. Additional information added

	considering the timescale of the process, and the use of devices such as cool cots, as some communities have particular requirements regarding the timing of a baby's funeral. These choices should be documented on the Bereavement Care Checklist and reviewed where they are relevant to process such as rapid release (NBCP Standard 3) At the end of the Cultural and Spiritual sensitivity section please add in The offer of memory making should be recorded on the Bereavement Care Checklist. This enables an evaluation of family experience and trauma informed practice at the CDRM (NBCP Standard 3). In the Targeted Support for Families Section (page 35) please change the first paragraph to There are particular groups who may need targeted or particularly tailored support through mortality governance processes, to ensure they are able to access the universal information and support available. When targeted or tailored support is indicated for families this should be recorded in Bereavement Care plans and the appropriateness/timeliness of this support should be tested at the CDRM. Where appropriate psychological actions should be included in PMRT Action Plans and monitoring undertaken. (NBCP Standard 4) The information below is not exhaustive and providers should discuss any particular support needs with families individually.	Included Added

	Support for Staff (page 37) please add a sentence to the end of the paragraph that starts Above all, it is of utmost importance that psychological professionals are… The uptake and effectiveness of support for staff should be monitored using staff well being markers, including retention and absence data, to ensure it meets needs (NBCP Standard 9). In the Debriefing to Learn section (page 38) add to the Aims Learnings from a debrief should be documented and captured into PMRT/CDRM Action plans.	Added Added
Josie Anderson On behalf of Bliss	**Introduction** Table 1 – Baby and family focused actions / 1-2 working days referral to bereavement services/lactation care for mother Ideally this should be 1-2 days, rather than working days. With regards to lactation support, if the mum wants access to medication to suppress supply or information about expression for donation then information and/access to medication may be needed sooner. This may be particularly pertinent if the baby has died soon after birth and the mum wishes to try and prevent lactation which may require medication to start on the first day postpartum (BAPM, Lactation and Loss). Tying this to working days could lead to these referrals/access to care not	Clarified in the table.

	happening for 4 days if falling around more significant bank holidays, which risks leading to increased distress.	
	Care of Baby and Family It is welcome to see the importance of family support and communication emphasised in this section. It would be beneficial if these statements, "The extent of involvement should be agreed with the family and amended over time according to their wishes" and "Families should be consulted on how they would like to receive information, and this should be reviewed throughout the process", were elevated to key principles or included in checklists for training materials. This acknowledges that individualised care is crucial component in tackling health inequalities. Some parents may experience barriers to attending their Child Death Review meetings due to issues with transport and childcare, and these circumstances should be proactively assessed and included in bereavement support planning. We recommend adding specific references in this section that access to appropriate interpretation services when end of life/bereavement options discussed should be available as far as possible. Reiterate that family members must not be used to interpret unless an emergency, and children must never be used to provide interpretation (Sands and Bliss (2018), Audit of bereavement care provision in UK neonatal units). We would also suggest this section recognises the importance of maximising care opportunities/involvement of	We agree with the views expressed but would leave this for individual units to implement. Added in with reference: • Interpretation services should be used to support good communication if either parent does not speak English fluently. Family members should not be used to interpret.

	families/addressing barriers from start of neonatal admission. Empowering parents to be parents and memory making throughout their baby's life is critical when a baby dies in NNU. Missed opportunities take on new meaning after death. Add reference to BAPM FICare framework in this section. Postmortem examination: Possibly highlight here that pathology services for babies who die in Northern Ireland are undertaken at Alder Hey, and so baby will need to be moved to England.	Included in appendix 1 with other references to memory making. Included the following: o Perinatal postmortem services are not available in many hospitals and families should be made aware that this may require their baby to be transferred to a more distant hospital. In Northern Ireland, transfer to Alder Hey hospital in England is currently required(ref)
	Reporting, Review and Dissemination of Learning It is really welcome to see such robust recommendations around breaking down barriers to sharing learning in this document. The core perinatal mortality governance team should consist of…MNVP…or PAG'': we would suggest strengthening this recommendation to say these reps 'must' have access to psychological support. Can more be said about what support for those doing this work should look like, outside of the psychological support offer? E.g. what training should be in place? Additionally, should access to support also be available to professionals involved in this work, too? ''Keep families informed…'': mention that those processes should ensure families have a single point of contact as far as	The working group felt that the current wording should be used. Communication with families strengthened in Family support and communication section.

	possible (e.g. their key person) and that there are opportunities for 2-way conversation – e.g. parents being able to talk to someone and ask questions about any developments. Consider adding into the 'dissemination of learning'' section to be mindful about when and how communications are sent. It can be very difficult if updates/information are sent on a Friday afternoon, for example, when the family realistically has no-one to follow up with until Monday.	In Dissemination of Learning - Changed to • Keeping families informed (via the key worker/lead consultant) about dissemination and implementation of actions is an important part of the grieving process and processes should be put in place to keep them informed. Consideration should be given to ensure information is not sent to families at a time when no one will be available to answer their questions.
	Appendix 1 – Supporting Families and Staff This appendix should reference communication barriers and how the process is managed in instances where families do not speak English as a first language. As per our comments earlier in the consultation, this section should stress that family members should not be used to interpet except for in extreme circs, and that children should never interpret. ''Families may find that a process of memory making at or near the end of life aids process of grief and loss'' We strongly agree and it is welcome to see this stated. However, there is a missed opportunity to discuss involvement in care while on the neonatal unit, before 'memory making' phase once death is expected. Many babies who die in the neonatal period will have a neonatal admission, and some will be a few weeks old before they die (or older, but think this is out of scope). Neonatal units should strive to support and empower families to be partners in delivering their baby's care throughout. Suggest signposting to	Added in Added in

	Baby Charter and to Bliss/Together for Short Lives 'caring for your baby when the future is uncertain' resource. ''parents with further needs'': It is extremely welcome to see this section, and while the specific focus on Autism and learning disability is great to see, we would suggest expanding this section more widely to cover guidance for a broader range of needs, including neurodivergence, physical disability & accessibility needs, and communication needs including no or low-levels of spoken English and poor literacy). We would also suggest turning the final paragraph 'adults with learning disabilities…'' into a more general paragraph on supporting communication. The points around easy-read resources and extra time, are also relevant to parents with varying communication needs & advocacy services are also relevant to some parents with mental health difficulties, or who have other complexities in their lives. We appreciate this is a hard section as it is not possible to specify every need, and associated support measures, but it isn't clear why autism and learning disability have been highlighted specifically. More general guidance which is applicable to multiple needs, coupled with more specific guidance to a wider range of common needs (if there is space) may be more useful.	We agree and have modified the guidance to cover the categories you have suggested in the supporting families/parents with further needs section. We have not expanded the section
	Appendix 2 – National Guidance	Not in this section as no other pathology services included in the table. We have included the following in PM section:

	As mentioned in an earlier box, this may also be a good place to include guidance around post-mortem in Northern Ireland, as this service is run out of Alder Hey? To note on <24 week certificates – the Northern Ireland Executive is consulting on this, so there may be a forthcoming change which might need to be reflected in this document.	○ Perinatal postmortem services are not available in many hospitals and families should be made aware that this may require their baby to be transferred to a more distant hospital. In Northern Ireland, transfer to Alder Hey hospital in England is currently require[i] Thank you for the alert – we will add if this becomes available in time.
Jane Gill Individual	**Introduction** Table One Prior to Death within the Statutory/ National Safety Notifications column Early contact with ME/ HMC or PF should also occur if solid organ donation is being considered. Immediately after death Organ donation consent would take place BEFORE death in the case of solid organ donation (prior to reorientation of care) I would remove the duplication about contacting SNOD/ TS from Staff Actions in this row as it is duplication and should happen before death Please could I suggest that the word 'verify and document death' which is used in Staff actions be changed to diagnose, confirm and document death. Within the AMORC document we	Added Removed Changed

	sought (with all key stake holders) to unify how we describe the process of diagnosing and documenting death and it was agreed we would encourage moving away from verification as a word.	
	Care of Baby and Family Thank you very much for referencing the new communication section in the AMORC code of practice.	 You are welcome
	Child Death Review - Immediate Decisions Again in this section please could I ask that Verification of Death (Changed to Diagnosis and Confirmation of Death) • Confirmation of the diagnosis of death in most neonates will be following cardiorespiratory arrest. Occasionally, a diagnosis of death is made using neurological criteria 29. I wonder if it might be clearer to say confirmation of the diagnosis of death will be made with cardiorespiratory criteria in most neonates. This is because arrest for some indicates an acute event rather than a withdrawal of ITU care.	 Changed Changed. Changed
	Appendix 3 – Case Examples I think these are excellent!	 Thank you
	Any other comments Congratulations on a really great piece of work. It is well written and comprehensive. There is a lot of variation in coronial	 Thank you

	processes between areas. Some work to harmonise processes would be welcome.	
Kirsteen Mackay Individual	**Care of Baby and Family** Organ donation - even for babies . 37 weeks , organ donation services are very limited/non existent. This needs to be acknowledged in the framework.	Services vary across the country and we feel it is important to highlight that regular contact with SNOD teams should be occurring. The working group does not consider an addition is required
	Appendix 3 – Case Examples The involvement of JAR processes is a significant change for neonatal deaths. Case 7 - unless the staff involved in JAR have experience in neonatal care will they be able to contribute anymore than the ME & referral to the coroner.	We have modified this case slightly for clarification.
Victoria Puddy On behalf of a university hospital trust	**Executive Summary** Should mention working relationships and processes with the medical examiner service , as all deaths will be reviewed by this service if not taken up by the Coroner service PMRT information on use of the tool : who it covers is as follows : Systematic, multidisciplinary, high quality reviews of the circumstances and care leading up to and surrounding each stillbirth and neonatal death, and the deaths of babies who die in the post-neonatal period having received neonatal care; (not just death within 28 days . updated July 2025) , although this is not a MIS safety action one requirement yet . Should the wording not be emphasised	Added to point on good working relationships: • develop good working relationships and processes with the local Medical Examiner (Eng/Wales) and His Majesty's Coroner/Procurator Fiscal (HMC/PF), to enable clear communication channels and information sharing to best support bereaved families. Changed to: • use the Perinatal Mortality Review Tool (PMRT) to support the child death review meeting (CDRM) for all neonatal deaths in the first 28 days when neonatal care has been received, regardless of the location of death (can also be used for babies who die in neonatal units after 28 days).

	Should it not emphasise the importance of all speciality MDT involvement within the CDRM (it is not explicit This part needs clarification : Neonatal units should facilitate ODNs with the information required to facilitate this… should provide	Added bullet on representation and made more explicit in CDRM section: • Neonatal units should involve all staff who participated in the baby's care in the CDRM (including other speciality multidisciplinary teams). Changed facilitate to provide – thank you
	Introduction I think it should be clear that this document applies to babies who die within neonatal services , it implies it can just be applicable to those within 28 days	We have worded this carefully to include everything included within the scope. No change to document.
	Care of Baby and Family All parents should be offered a PM (this contravenes the Paediatric PM policy statement)	Parents should be offered a PM - this is a recommendation from RCPath and is also supported by SANDS and HTA. There is no current plan for RCPath to change guidance. We have added in that babies may have to travel to a more distant hospital for PM and parents should be made aware of this.
	Child Death Review - Child Death Review Meeting Emphasis on MDT engagement , all specialities and teams involved in the care of the baby should be part / represented at the CDRM , it is not explicit Need to highlight the importance of external representation at the meeting , it is not in this section	Thank you. We have added more about the multidisciplinary team in the first two bullet points around representation. External representation is specifically discussed in the representation at the CDRM section
	Any other comments	

	Overall an excellent document , well done for pulling together a complex multiple reporting and review processes across all the nations in a relatively simple document . Its very understandable and explanatory Thank you	Thank you for your kind comments
Laura Atherton On behalf of Milk Bank at Chester, Memory Milk Gift (Countess of Chester)	**Introduction** The framework states that lactation management should be discussed within 1-2 working days. This is incorrect and would mean that many families have their choices reduced rather than presented to them. Lactation should be discussed where death is anticipated if possible giving families time to consider their options and be involved in Shared decision making. This should include comfort care for baby, bonding and breast care Breast care should also be included immediately after death where death wasn't anticipated.	Included lactation and breast care in more places in Table 1.
	Care of Baby and Family Lactation management should be discussed with every family following an antenatal diagnosis or after loss, and the role doesn't necessarily fall to that of the infant feeding team. If the infant feeding team are unavailable, choices should still be offered to families and so the identification of the IF team as those to offer this choice means that families will miss out on the choices available to them.	**Section on lactation modified and expanded as follows:** • Mothers/birthing parents should be given support to manage lactation and breast care in the event of neonatal death, including discussing and facilitating donation of breastmilk. • Breastmilk donation after neonatal death (sometimes called "memory milk gifting") can provide comfort to

	The BAPM framework for Lactation and Loss outlines the choices available to families and more information on breast care choices, lactation information and milk donation after loss can be found on the Milk Bank at Chester website - home to the national initiative Memory Milk Gift - which all UK milk banks are signed up to (www.milkbankatchester.org.uk/donationafterloss) It is key to mention that without offering all lactation choices to families, and solely offering medication for lactation suppression as per outdated guidelines leads to questions around informed consent. NHS learning hub course - https://learninghub.nhs.uk/Resource/51570/Item#:~:text=Lactation%20After%20Loss%3A%20Choices%20for%20Bereaved%20Parents&text=This%20course%20is%20designed%20for,course%20beneficial%20for%20their%20studies.	some mothers/birthing parents and families. Staff should be aware of the schemes available in their area. • Details of lactation options available after baby loss are outlined in the BAPM Framework for Lactation and Loss (ref) and e-learning is provided on the NHS learning hub (ref) . • Practical and emotional support for parents is available through the National Breastfeeding Helpline Also included the following in the executive summary: • Neonatal units should provide support for managing lactation and breast care in the event of neonatal death, including discussion and facilitating donation of breastmilk. We have added in this reference – thank you
Nicholas Embleton Individual	**Appendix 1 – Supporting Families and Staff** 1) Overall, this is a great document and links out to other work in the area. But there are at least two link outs to private business run by clinical psychologists offering paid-for therapy as well as training etc. and I wondered what the committee think of this? There are some very good private training providers but equally many charities offer paid-for training. I don't know how/why some of these specific business were	Thank you. We have removed any links to private training providers and have added your fabulous resource information to the supporting skill development for staff section. • Best practice in perinatal palliative care; this is a 4-hr free NHS resource based on the BAPM palliative care framework o Future Learn_Managing Uncertainty in Perinatal Medicine and Palliative Care

	included - I can't see how they are linked to NHS - maybe I am missing something and they are commissioned services in which case fine. But if members of the working group also operate a business that might benefit from this promotion presumably they should be declared as conflict of interest? 2) We have now launched our 4-hour online training resource on Managing Uncertainty , based on the BAPM framework and widely supported by multiple charities and advocacy groups. This is available from https://www.futurelearn.com/courses/managing-uncertainty-in-perinatal-medicine-palliative-care/1 and from https://learninghub.nhs.uk/Resource/63157/Item where it is FREE for NHS and there is certificate for CPD. The course covers multiple areas similar to this current framework and is fully aligned. Great if you can highlight that free NHS resource. I don't believe there are any conflicts of interest and we don't make any money!	o My Learning Hub Managing Uncertainty in Perinatal Medicine and Palliative Care .
	Any other comments the point i raise above might irritate people so think about whether you want to anonymise that comment! happy to discuss. equally i don't mind being named!	Your comment is very welcome – thank you
Suzanne Sweeney On behalf of The London Neonatal Operational Delivery Network	**Executive Summary** In the London region there is huge variation in CDOP processes and levels of information sharing which is largely outside of the ODN control. There is duplication in reviews	We hope this document helps to make this clearer. Your comments will be passed on to the national group looking at reviewing the statutory CDR guidance in England.

	PMRT/CDRP/CDRM and very limited support at ODN to bring all of this together - it requires a wider system approach.	
	Any other comments Draft guidance is still confusing as PMRT and CDRM are used synonymously. It doesn't refer to the separate issue of children's hospitals without maternity services.	We acknowledge that different terms are used locally and indeed the PMRT is a tool which can be used for the purposes of CDRM. The beginning of the child death review meeting process section describes the terminology that we use – we refer to the process as the CDRM throughout. We have clarified the point regarding neonatal deaths outside of neonatal services: • Across the UK, the PMRT process should be used for all neonatal deaths in the first 28 days when neonatal care has been received, regardless of where the patient dies. For deaths in other locations in the first 28 days, when neonatal care has not taken place, e.g. Paediatric Critical Care, consider use of PMRT and if this is not possible, careful consideration of perinatal factors should be incorporated into the CDRM and CDOP (Eng) reviews, and the PMRT should be closed.
Emma Thomas On behalf of The Breastfeeding Network	**Executive Summary** Under Recommendations for Neonatal Units, Care of baby and family, we suggest adding that all units should provide support for managing lactation in the event of neonatal death, including discussing and facilitating donation of breastmilk, sometimes known as "Memory Milk Gifting".	Added to exec summary and altered text in main body to match.
	Introduction	

	In table 1, column "Baby and Family Focused Actions", row "Prior to death where anticipated", we suggest adding an action to discuss lactation care if the mother/birthing parent is lactating, including the possibility of donating breastmilk after neonatal death. We recognise that lactation care is included in the row "1-2 working days", but suggest that where death is anticipated, it could be helpful to open the conversation earlier. We also note that lactation care may be needed after the first 1-2 days, up to 3 months or more, depending on the parent's choices.	Changes made to table to include in all sections up to 3 months.
	Care of Baby and Family Section: Lactation care. We suggest expanding on the existing text to note that breastmilk donation after neonatal death, sometimes called ""memory milk gifting"", can provide comfort to some mothers and families. Donations can range from a single donation to an ongoing donation process over weeks or months. Staff should be aware of the schemes available in their area. See https://www.milkbankatchester.org.uk/donationafterloss/ for more information. The details of the National Breastfeeding Helpline (NBH, https://www.nationalbreastfeedinghelpline.org.uk/) could be provided as a qualified source of ongoing practical and emotional support regarding expressing breastmilk and ending lactation for all mothers and birthing parents. All supporters on the NBH have received a high standard of training, equivalent to level 3, including counselling skills. Theya re able to create a	Section expanded to include: • Mothers/birthing parents should be given support to manage lactation and breast care in the event of neonatal death, including discussing and facilitating donation of breastmilk. • Breastmilk donation after neonatal death (sometimes called "memory milk gifting") can provide comfort to some mothers/birthing parents and families. Staff should be aware of the schemes available in their area. • Details of lactation options available after baby loss are outlined in the BAPM Framework for Lactation and Loss (ref) and e-learning is provided on the NHS learning hub (ref). • Practical and emotional support for parents is available through the National Breastfeeding Helpline

	safe space to listen, signpost as appropriate and have access to ongoing supervision to keep the service safe when dealing with trauma. We also suggest that this section should refer and link explicitly to the BAPM Framework Lactation and loss: Management of lactation following the death of a baby for more detailed information, as this is a crucial document.	
	Staff Considerations We suggest adding a bullet highlighting the need for staff to be trained in managing lactation in the event of neonatal loss, and referring/signposting to relevant services including memory milk banking services and the National Breastfeeding Helpline.	Added
	Appendix 1 – Supporting Families and Staff We suggest that under the heading "Supporting skill development for staff", training in managing lactation after loss should be included, with reference to the BAPM Framework Lactation and loss: Management of lactation following the death of a baby. Both practical and emotional support specific to lactation will be required by all lactating parents, and specific training is essential. For information and training relating specifically to lactation, staff could contact the Breastfeeding Network: www.thebreastfeedingnetwork.org.uk.	Added
Craig Smith Individual	**Executive Summary**	

	"have access to suitable bereavement facilities, and families should be given pragmatic options for where end of life care takes place." Is this a recommendation for service delivery rather than governance?	It is strictly speaking but the working group have considered care of the baby and family to be of utmost important and have retained this bullet point.
	"use bereavement checklists which are consistent with national and statutory guidance" This shouldn't be the first item on the Child Death Review list. The first item could be: Be familiar with their local Child Death Review team and CDOP "be familiar with national statutory/legal processes and child death review processes in their locality. Best Practice recommendations regarding completion of the medical certificate of cause of death are outlined in the Registering the death section, with specific case examples in Appendix 3: Case Examples" These 2 sentences should have separate bullet points as are separate issues	Thank you – first 3 bullet points in CDR now read: All units should • be familiar with national statutory/legal processes and child death review processes in their locality. • adopt best practice recommendations regarding completion of the medical certificate of cause of death. These are outlined in the Registering the death section, with specific case examples in **Appendix 3: Case Examples**. • use bereavement checklists which are consistent with national and statutory guidance (**Appendix 2**). Done – see above
	"develop good working relationships and processes with His Majesty's Coroner/Procurator Fiscal (HMC/PF), to enable clear communication channels and information sharing to best support bereaved families. Families should be consulted on how they would like to receive information."	No, we are not suggesting a separate coroner liaison role. This is a more general point for the unit to ensure good working relationships with the local ME and HMC/PF - that they are

	Not sure what these mean. Are you suggesting each service has a Coroner liaison role? The established and statutory 'Key worker' and bereavement team lead on family liaison. Are you suggesting clinicians 'double up' on this role or do you wish to make clear it is the Key worker role to do this? Also, May need to be clear about what is a keyworker and what is bereavement support as these roles are different across different Trusts. Some areas have both, some have one and some have none. According to the child death statutory guidance they may be 2 different roles. "All bereaved families should be given a single, named point of contact to whom they can turn for information on the child death review process, and who can signpost them to sources of support". The term bereavement support means different things in different areas, for some it is signposting to bereavement support services (much like a key worker) while to others it is providing bereavement services themselves, and thus, this is a more extensive support service. "use the Perinatal Mortality Review Tool (PMRT) to support the child death review meeting for all neonatal deaths in the first 28 days" Do you mean BAPM only supports this tool? Can other similar tools/processes be used? Or do you mean this tool should be used by trusts signed up to the MIS?	easily contactable and that individual named consultants/key workers can communicate readily directly when needed and vice versa. There is some flexibility required to allow for different models across the UK. We feel the key requirements are outlined in the third bullet point of the care of the baby and family section. We have changed family key worker/bereavement lead in favour of family key worker in Table 1. We have clarified the statement to read: • use the Perinatal Mortality Review Tool (PMRT) to support the child death review meeting (CDRM) for all neonatal deaths in the first 28 days when neonatal care has been received, regardless of the location of death (can also be used for babies who die in neonatal units after 28 days). We have provided a clarification in the body of the report for deaths occurring outside neonatal units when neonatal care has not been given as we feel that perinatal information can still be highly pertinent to deaths in the first month after birth. Part

	The PMRT is poor for deaths after the first week or for those who die elsewhere and don't use the tool. "The term Child Death Review Meeting (CDRM) is used throughout this document to describe the local health professionals review of the care of a baby that has died. Locally, different terminology is often used e.g. local Morbidity & Mortality meeting, Perinatal Mortality Review Tool (PMRT)". According to the child death review statutory and operational guidance, CDRMs are multi-agency meetings which should include health professionals involved with the care as well as social care if involved with the family, ambulance, primary care clinicians and schools. Not every trust has these in place yet, so PMRT and M&Ms are being used. "use a trauma informed approach" This will be jargon for lots of readers. May be better in plain English or explained. "ensure the child death review meeting is conducted in accordance with national and statutory guidance.."	of the reason for this is that the PMRT is very good for reviewing pregnancy, labour and birth care which may be where, had different care been provided, the outcome may have been different. • Across the UK, the PMRT process should be used for all neonatal deaths in the first 28 days when neonatal care has been received, regardless of where the patient dies. For deaths in other locations in the first 28 days, when neonatal care has not taken place e.g. Paediatric Critical Care, consider use of PMRT and if this is not possible, careful consideration of perinatal factors (particularly antenatal, labour and birth care) should be incorporated into the CDRM and CDOP (Eng) reviews, and the PMRT should be closed. We understand that different terminology is used in different places which is why we have clarified the terminology. A neonatal CDRM may indeed have social care, and ambulance workers involved if they have been involved with the care of the baby. We have added an additional point regarding all professionals to be involved in the CDRM. The trauma informed approach is explained in Appendix 1

	This statement merges the existing Child Death Review team/CDOP role with the 'newer' PMRT function (which evolves and expands each year). The former represents the anonymous collection of data for Public Health level learning, the latter is becoming a parent led review of individual cases. This working group needs to very clearly differentiate between these two functions as they have different outcomes, require different resources and impact families and staff differently. Non-anonymised reviews are labour intensive and more associated with medico-legal consequences	We disagree with the comments regarding PMRT as the description does not match PMRT processes and outputs. PMRT provides a standardised structured approach to reviewing the whole care from antenatal, labour and birth to postnatal and bereavement care. PMRT provides excellent population level anonymised reports as well as important trends at national level.
	Introduction This is too short and is a missed opportunity to explain the very significant changes of the last decade: UNICEF programme and data on falling NMR, development of HSIB/MNSI, merging of National Child Mortality databases, emergence of the PMR tool, the shift from anonymous system based learning to individual parent led/informed learning, the introduction of the ME system, the rise in concerns about maternity and neonatal services, the expectation NMR will always continue to fall, the focus on hospital services rather than public health issues and government funding, impact of mass migration, indigenous population based guidance versus individualisation for all, NHS Resolution, rising medico-legal costs associated with non-anonymised review processes, etc	Framework documents are designed to be as short and focussed as possible. The information contained in this document is already very dense. The suggested additions would be excellent in a paper of their own but we did not feel that these additions are needed in this document.
	Care of Baby and Family	Changed to:

	"There may be several reviews and families should be informed about the timelines; asked if they wish to contribute and receive regular updates" What is the evidence base for this? Do ALL families want this, especially if they have been satisfied with care and explanations? Or is this what a minority of parents want? Receiving separate letters or phone calls or visits so say a mortality meeting has taken place, a network discussion has taken place, a CDOP discussion has taken place etc., where there are no new findings, may delay their bereavement journey or leave them with an impression something may have happened they weren't told about. "All families should be offered the opportunity to discuss the wording of the Medical Certificate of Cause of Death (MCCD) and ask any questions about their baby's care" Shouldn't this be 'the words used on the MCCD should be explained and if necessary, translated for parents? Also, this sentence needs breaking up as asking questions about care is a separate issue, although it may be done around the same time. "Compassionate support and communication from the named consultant and keyworker should be maintained throughout His Majesty's Coroner/Procurator Fiscal (HMC/PF) or Maternity and Newborn Safety Investigations (MNSI) processes. "	• There may be several reviews and families should be informed about the timelines and asked if they wish to contribute • Families should be consulted on how they would like to receive information, and this should be reviewed throughout the process. These points have been separated and modified slightly • All families should be offered the opportunity to explain and discuss the wording of the Medical Certificate of Cause of Death (MCCD). • All families should be given the opportunity to ask questions about their baby's care with the lead consultant and in England and Wales, separately, with the Medical Examiner. • Interpretation services should be used to support good communication if either parent does not speak English fluently. Family members should not be used to interpret (ref).

	This is only possible if the coroner approves the communication and is informed of the content.	This is not correct. HMC/PF do not have to approve communication.
	Child Death Review - Immediate Decisions "Involvement of families in the Child Death Review Meeting (CDRM) improves dialogue and continuity of care between parent(s) and providers and empowers parent(s) to maintain a purposeful role following the death of their baby. " Is there sufficient evidence for this statement? Reference 19 was a very small study involving just 4 NNDs and no complaints. Do we have the resources to extrapolate this position to all? Also, according to the child death statutory guidance- "The CDRM is a meeting for professionals. In order to allow full candour among those attending, and so that any difficult issues relating to the care of the child can be discussed without fear of misunderstanding, parents should not attend this meeting. However, parents should be informed of the meeting by their key worker and have an opportunity to contribute information and questions through their key worker or another professional". Is it the position of this working group we move towards parental attendance as the norm? The ME must also sign the MCCD	The bullet points has been modified to make it clearer that parental input is welcomed but that they will not be in attendance at the meeting: • Involvement of families in the Child Death Review Meeting (CDRM) improves dialogue and continuity of care between parent(s) and providers and empowers parent(s) to maintain a purposeful role following the death of their baby. The key worker should support the family to prepare questions/comments for submission to the CDRM. Families' views should be heard and questions answered at the CDRM. Agreed – this is included in the ME section.

	"In babies over 24+0 weeks gestation, it is not usually appropriate to write the main cause of death "Extreme prematurity" without justifying it with further diagnoses or information." Are you saying 'Extreme Prematurity' shouldn't appear in section (a) of the MCCD unless under 24 weeks?	No – we are saying it shouldn't be a standalone diagnosis without other information on the death certificate to explain the cause of death.
	"A JAR/PRUDiC should also be triggered if a baby is successfully resuscitated after any of the above events but is expected to die in the following days. In such circumstances the JAR should be considered at the point of presentation and not at the moment of death, since this enables an accurate history of events to be taken and, if necessary, a 'scene of collapse' visit to occur. " It would be really useful to provide a list of examples of this as many are unclear about when to consider a JAR, and it is likely this varies from Trust to Trust.	We have given examples of when a JAR/PRUDiC should be considered in a neonate but we recognise that remains a grey area. We will forward your comments for consideration by the CDR statutory review update which is about to take place for England.
	"If the birth has not been registered before the baby's death, the team should inform the Registrars as both registration of birth and death would need to be done at the same time". This is a parental choice; they can register the birth and death separately if they wish, as long as the registrations are within the legal time frames.	Changed to "can be done at the same time"
	Child Death Review - Child Death Review Meeting	

	"Identify the cause of each baby's death" "Provide parent(s) with a robust explanation of why their baby died" For the majority of babies, this will have been done at the time of the death. Should this be 'confirm the cause of death' and provide parents with any new information, as necessary' "Develop action plans to address the modifiable contributory factors identified and achieve organisational change and service improvements." Should this be 'inform the established Quality Improvements Systems and Personnel to achieve organisational change and service improvements' It would be worth reflecting how difficult it is to get everybody involved in one room at one time AND how much resource this represents, given the current NHS plan is to move/return resource to clinical care. "The PMRT should be completed at the CDRM. " This needs to be more flexible i.e. 'should be completed in association with the CDRM' as the process of data entry disrupts discussion and is very time consuming. Also, according to the child death statutory guidance the child death review analysis forms also need to be completed at the	Aims of the neonatal CDRM review first bullet point changed to • Identify/confirm the cause of each baby's death by robust and comprehensive review of each case and the quality of care provided. We have left the parent and action plan development points unchanged. Whilst we agree this is challenging we think this is worthwhile and is being achieved in many services. We give some indication of what should be included for staffing support in the document Modified to: • The PMRT should be completed at or shortly after the CDRM. In England, the CDR draft analysis form also needs to be completed and submitted to the Child Death Overview Panel (CDOP) for final independent multi-agency review. In Scotland, the CDR Core dataset should also be completed at or shortly after the CDRM.

	CDRM which will make these lengthy meetings for every neonatal death. “After the review meeting parent(s) should be offered a meeting to discuss the findings and outcome of the review meeting. ” Is this always necessary? Is this done by the PMRT team or should it simply be fed back by the named consultant and key worker as part of the established bereavement process? This suggestion to regularly meet with parents requires significant resources.	The discussion with parents should be with the named consultant. The bullet point has been changed to: • The named consultant should offer families the opportunity to meet to discuss the outcome and any actions following the CDRM.
	Reporting, Review and Dissemination of Learning “Parent voice representatives should have access to psychological support when undertaking this work. ” The document should take every opportunity to say that all those involved in mortality work should have access to psychological support, to make clear throughout everyone may be impacted by the death or the processes that are associated with it.	We agree and have modified the statement to read: • Staff and parent voice representatives should have access to psychological support when undertaking this work. We include further information in the staff support and training section and in Appendix 1.
	Staff Considerations “a dedicated consultant ”	We have made this more flexible: • Each unit should have dedicated consultant and senior nurse leads for mortality governance with dedicated time to lead neonatal Child Death Reviews, thematic review, attendance at

	At NICU level this should be a team of Consultants given the burden and number of cases and complexity that can arise from some cases.	CDOP, and for dissemination of learning and assurance processes.
	Appendix 1 – Supporting Families and Staff Reference 24 (page 33): This position results from a very small study and the use of the word 'should' throughout suggests this should be established practice and is beneficial to the majority. Although this work is plausible, it may represent a minority position and may require significant resource to develop and deliver. Page 36: "Support for staff": It would be useful to add a line that staff expect to be treated reasonably by other stakeholders such as parents, colleagues, Trust management and the coroner. This is not always the case and this document should help set this standard. In terms of wider Mortality Governance, it would be worth adding a section on large external reviews e.g. Ockenden, Amos etc touching on the impact on staff and the need to treat staff respectfully and follow evidence based processes AND be relatively time limited. The 2 consecutive 'independent' reviews in Nottingham have been going on for over 4 years and have been repeatedly extended with no prospective parallel plan to assess impact on staff and services under 'intense scrutiny'.	The study is small but provides useful information which people may want to consider. We have added "recommendations you may wish to consider" to make it clearer. We have added an additional point: It is important that staff feel safe in their workplace and should expect to be treated reasonably by other stakeholders, such as parents, colleagues, their employing organisation and external representatives e.g. HMC/PF/MNSI/external reviewers. Trusts should have processes in place to respond constructively if this does not happen. We have included external reviewers to the bullet point above and have included the need for staff support during any external investigations in the staff considerations section. • Specific staff support should be considered for services under intensive scrutiny e.g. during an external review.

	Is it beyond the remit of this 'governance' document to set out the principles of large service reviews which include mortality reviews from the learning from Morecambe Bay, East Kent, Shrewsbury, Nottingham etc, to create a more useful template of how to do these? Without this learning, future reviews may be poorly constructed and executed.	We feel it is beyond our remit to go any further with regards to principles of large service review.
	Any other comments Nicely set out. Format and font easy to read. Useful repetition throughout the document. Includes the important awareness of impact of mortality and mortality governance and multiple and prolonged processes on staff. Includes the important inclusion of some of the resource issues-this could be expanded and made very clear for commissioners and Trusts.	Thank you.
	The title is confusing: Is this about how established and new mortality systems are managed i.e. governance? Or is this a collection of best practice points, or both? You may need to change the title to reflect both elements.	This is a best practice guidance and so is a combination of both. We recognise we have also included some elements of care which are not strictly part of governance, but we feel they are important to include together. We have chosen to keep the current title for simplicity.
	With the emergence of PMRT there is lots of duplication with the child death review process and lots of new work. It is worth making clear the differing principles and purposes of the statutory child death review processes and PMRT.	The relationship between the PMRT and CDR process are clearly outlined in the statutory guidance and make it clear that the CDRM will often be known as a PMRT review group meeting. Regarding the structure of the PMRT, from the outset the PMRT team has taken a view that the PMRT must be parent informed.

	The significant shift for PMRT to be parent informed or led has a relatively small evidence base and I wonder whether this has been fully explored and the resource implications considered. Extra bits for Executive Summary: "provide quality assurance around the CDRM process, including reviewing representation at CDRMs, appropriate family input and response to their questions, PMRT outcome gradings and learning outputs. Neonatal units should facilitate ODNs with the information required to facilitate this." Isn't this really a Trust responsibility under the Learning from Deaths national agenda? "Themed' neonatal CDOP meetings are strongly recommended, to ensure that maximum learning is derived through aggregate review of deaths. CDOPs are strongly encouraged to share learning with the neonatal ODN." This may need clarification. Do you mean the CDOP should set aside some meetings to discuss only neonatal cases and invite experts along, or do you mean they should set aside a number of meetings to cover neonatal themes such as 'infection', 'extreme prematurity' or 'congenital anomalies'?	This position has not changed to the PMRT review being parent-led. The neonatal ODNs have an important assurance role as well as trusts. Themed CDOPs are described in the statutory guidance. We mean the former – they should set aside some meetings to discuss only neonatal cases. We have made this clearer in the CDOP information in the main text.
Alexandra Mancini Individual	**Executive Summary** Care of the baby and family-consider these changes	We have included the following bullet point at the beginning of this section

	-there should be greater emphasis on emotional & psychological support for the family in this 1st section, including cultural humility and alignment. Families may have the opportunity for planning care antenatally or at delivery -'named keyworker' should be specific -Bereavement Midwife or Neonatal Palliative or Bereavement Care Nurse-NCMD Report 2024 is specific -include staff must be provided appropriate support -clarification on 'bereavement facilities'	• Neonatal units should use their country's National Bereavement Care Pathway (NBCP) for pregnancy and baby loss to guide provision of high-quality compassionate care to bereaved parents and families. We have now clarified the specifics of the key worker We have not expanded on the last two points in the exec summary but include in more detail in the body of the document.
	Introduction There is a sentence at the end of the 1st paragraph, signposting to Appendix 1. I think it should be considered appropriate to add the 1st 2 paragraphs from Appendix 1'Supporting families & staff' in this section to explicitly focus on the support families may require and placing them central to the framework. The timeline is very helpful, but think there could be some key changes to add greater importance to various sections and bullet points. There appears to be a focus on discussing Organ Donation. In recent months there has been a move away from this approach to care and including these discussions as part of advance care planning. Throughout the timeline from the very beginning, prior to death where anticipated through to >3months, parents have access to named keyworker if they wish, as and when they require it. But also the key worker makes regular contact (prior discussion	Added to introduction. This is listed in the timeline. Has been removed from immediately after death section and only included in "prior to death where anticipated" section. Added to all sections.

	with the family if this is what they would like) to ensure they are supported throughout this time. PRIOR TO DEATH WHERE ANTICIPATED Consider -Parallel planning/treatment options/comfort care (in reference to the BAPM framework'Recognising uncertainty...' we are moving away from this term. -breast care and lactation choices discussed rather than waiting 1-2 days post death -identify lead consultant and family key worker(Bereavement Midwife /Neonatal Nurse) -collaboration with local children's hospice and/or specialist palliative care team -if the family wish, discuss the physical changes of their baby after death and what happens next -'Religious rites' add cultural beliefs/family traditions SECTION STAFF ACTIONS-unclear what 'documentation of palliative care' means IMMEDIATELY AFTER DEATH -Care for the baby's body with dignity -use of 'cold cots', consider adding there are alternative cooling technologies and if the parent's wish and no coronial process in place, parents may wish to use a temperature controlled bedroom at local hospice -discussion how baby's body may be transported to the mortuary-this may also be discussed prior to the death where anticipated	 Changed to parallel planning/treatment options/palliative care Lactation and breast care included in all sections Named specifically in first staff action box Added Added Added Changed to Documentation of Advanced Care Plan/Family wishes Added Added in abbreviated form – more detail included in body of document Added

	-identify lead consultant and key worker at the earliest opportunity, wherever possible prior to the death 1-2 WORKING DAYS -Hot debrief (if required) are these not always required as good practice? and on the day of the event to ensure all staff members are present before the end of the shift -notify relevant health professionals-consider moving this to immediately after death, as a delay in informing may result in the family being contacted by them FIRST WEEK -ongoing contact with family keyworker/bereavement lead-as above Throughout the timeline from the very beginning, prior to death where anticipated through to >3months, parents have access to named keyworker if they wish, as and when they require it. But also the key worker makes regular contact (prior discussion with the family if this is what they would like) to ensure they are supported throughout this time. This to include support for siblings and the wider family. Acknowledging that there may also be a surviving twin or triplet which the family are also caring for 1 WEEK-3 MONTHS -offer the family a Bereavement meeting/opportunity to meet, even if the investigations are not completed. The family may have questions and may value a meeting regardless	Included (if required) removed. Left as 1-2 days as staff are often looking after the baby for some time after the baby has died and may not be available for debrief. Left as 1-2 working days. Added Changed accordingly
	Care of Baby and Family	

	FAMILY DECISIONS AROUND THE TIME OF DEATH -a named consultant should be identified.....also a Bereavement Midwife or Neonatal Nurse LOCATION OF END OF LIFE CARE-care consider adding transfer to LNU or SC if the family wish to be closer to home ORGAN DONATION-there appears to be an emphasis here, please see previous comments. There should be inclusion in the framework, but it appears prominently POSTMORTEM EXAMINATION Sentence...The clinician or specialist nurse-add or Bereavement Midwife LACTATION CARE Expand on this area as mentioned previously, this should be included in choices for parents. Consider renaming Lactation Choices	Added Added We have left this section unchanged. The criteria are in a box to make it easier to read. Added Renamed Lactation Choices and breast care. This section has been expanded considerably following other comments.
	Child Death Review - Immediate Decisions Clarity in roles and responsibilities COMMUNICATION WITH HMC/PF-this may be alongside the Bereavement Midwife or Neonatal Nurse	Clarified: • The named consultant should support the family (alongside the bereavement midwife/neonatal nurse) and liaise with HMC/PF team.
	Child Death Review - Child Death Review Meeting Clarity in roles and responsibilities	Roles clarified
	Reporting, Review and Dissemination of Learning	

	Figure 1 is particularly helpful demonstrating an overview	Thank you
	Staff Considerations -Typo- page 23 under Staff Considerations -1 x WTE Band 7 Neonatal Nurse -add clarity on specifying how staff are appropriately trained by completing the SANDS NBCP Training -Dedicated time required to support mortality governance is clear in it's messaging and recommendations	Added re SANDS NBCP training in main document and highlighted more in appendix.
	Appendix 1 – Supporting Families and Staff This is an excellent addition to the framework, but think there are sections which may fit better at the beginning of the document 'A compassionate, trauma-informed framework' would work well at the beginning of the framework, highlighting the parent experience Supporting skill development for staff section: The link to a company who charge for training https://bereavementtraining.com should be removed and should not be placed alongside the link to the National Bereavement Care Pathway which is referenced throughout the document ats the training healthcare teams should access and complete and is free of charge and accessible on the NHS learning hub.	We have included more about the families in the introduction but the details of the trauma-informed framework are in the Appendix.

	As a professional body , I would not expect BAPM to demonstrate an allegiance with a business, for profit organisation which may be perceived as favouring them over the very well respected and established training which is available free at the point of access, SANDS NBCP, Child Bereavement UK, Lullaby Trust and ARC There needs to be national consistency with approaches to Bereavement Training and this should be SANDS, National Bereavement Care Pathway which has been adopted by the majority of Trusts nationally	All private providers have been removed and there is better clarity around the key role of SANDS NBCP training.
	Appendix 2 – National Guidance The flowcharts give clarity and are easy to follow NBCP is referenced throughout	Thank you
	Appendix 3 – Case Examples These case studies are really helpful , detailing various processes and clearly showing the processes followed.	Thank you
	Any other comments I think this framework is an excellent opportunity for parents and the wider family to be at the very centre of extremely complex and challenging systems when their baby has died. I appreciate the framework is already lengthy, but feel strongly there are some changes and additions which could be made. The processes and statutory requirements are very clear and easy to follow particularly with the flow charts and will provide clear and concise guidance for perinatal teams.	We have tried to make changes to the document to reflect this.

	Appendix 1 is excellent in addressing the distress faced by families and what support they made, whilst also acknowledging the significant impact placed on perinatal teams. I feel much of the content should be at the beginning of the framework illustrating the importance.	
Robin Miralles Individual comments but also on behalf of Leicester Neonatal Service (UHL)	**Care of Baby and Family** Page 9 (care)- 'Postmortem Examination: All parent(s) should be offered a postmortem examination.' This is our current practice, but is the RCPath considering a change in guidance because of the shortage of perinatal pathologists?	Parents should be offered a PM - this is a recommendation from RCPath and is also supported by SANDS and HTA. There is no current plan for RCPath to change guidance.
	Child Death Review - Immediate Decisions With ref to Page 12- 'the named consultant should oversee the discussions and writing of the death certificate' (also page 14) We find it is usually the 'duty' consultant rather than the 'named' consultant who will oversee discussions and writing of the death certificate. Often the 'named' consultant will be determined at admission and may not be present at the time of death. With ref to Page 13, referrals to HMC- 'This does not have to be an error in care and could, for example, be a recognised complication of necessary	Adjusted to “The duty consultant (preferably the named consultant) ..”

	treatment. Referral in these cases should occur regardless of whether the cause of death is known and can be explained.' This is probably clear in most circumstances (e.g. acute events) but some further clarification may be needed here. With respiratory complications- would PIE and severe chronic lung disease be considered a complication of treatment in an extremely preterm infant?; or a pneumothorax in a ventilated patient with severe pulmonary hypoplasia due to LUTO or renal dysplasia? With ref to Page 14- 'Hypoxic ischaemic encephalopathy -There should be a very low threshold to refer such cases to HMC/PF.' It would be useful to clarify here the benefit of referring these cases over and above a detailed hospital investigation. We note the comments on HMC proceedings on page 36 (below)- the timescale of review and impact on families. Acknowledged that referral likely to be needed where multiple healthcare services involved. (Page 36- Families going through coronial proceedings: The particular stresses of a coroner's investigation cannot be underestimated. In fact, the counter-therapeutic impact for families of coronial investigations has been highlighted (34)) With ref to Page 14- Sudden Unexpected Death	We feel this does not need further explanation as the sentence follows on from a description of what constitutes an unnatural death. We have added further explanation in the case studies to help with this. We stand by this statement. HIE should always be justified by a natural reason. We explain this in more detail in case 6 of the case examples. In this document, we also ask neonatal units to develop good relationships with HMC/PF to improve the experience for families.

	'Deaths meeting the criteria for sudden unexpected death (SUDIC/SUDI/PRUDiC/SUPC) are uncommon in neonatal units.' Also the case that sudden unexpected deaths may occur on the postnatal ward (not just neonatal units). With ref to Page 16 'Notify via MBRRACE-UK CASCADE Process if baby < 28 days old for joint MBRRACE-UK and CDOP/NCMD notification. -Babies >28 days – notify using CDOP notification form' May need to indicate 'first 28 days' for clarity rather than < 28 days as has been done on page 18.	Added postnatal wards. Clarified.
	Appendix 1 – Supporting Families and Staff App1 (support)- page 33- Review timings may be significantly longer for multihospital complex reviews (often 2 or 3 hospitals have been involved in perinatal-neonatal care). Also review times lengthened by time taken for autopsy results to be released.	We have given some flexibility in the timing to allow for external processes. We feel the current timings are appropriate.
	Appendix 2 – National Guidance App2 (governance) - Page 46- 'Self-neglect' in the mother?	These are taken directly from HMC guidance. One would need to consider whether maternal self-neglect directly contributed to the baby's death.
	Appendix 3 – Case Examples	

	App3 examples - Page 54- Repeat of same table that is on page 44? (may have been intentional for easier reference). App3 examples - Page 57- with reference to HIE 'There should be a very low threshold to refer such cases to HMC/PF as not all information is available immediately following birth and issues of care that may have contributed are not known until a fuller investigation is undertaken.' Again it would be useful to clarify here the benefit of referring these cases over and above a detailed hospital review. We note the comments regarding HMC proceedings on page 36, the impact on families, and a significant delay in feedback from reviews.	This is intentional for reference. We stand by this statement. HIE should always be justified by a natural reason. We have added further explanation to case 6 of the case examples. In this document, we also ask neonatal units to develop good relationships with HMC/PF to improve the experience for families.
	Any other comments Overall a really useful document bringing together much of the relevant information on perinatal-neonatal reviews. Helpful worked examples. How to fund these reviews as outlined, especially tertiary-level external reviews, remains a significant concern. Centralisation of services means that a disproportionate number of reviews will be led by level 3 units with surgery (a much higher proportion than accounted for by local birth rates, possibly 5-10 times as many compared to local level 2 units-	Thank you Thank you for your comments. We do recognise that the reviews will disproportionally affect level 3 units and more time has been suggested in these units for leading governance activities.

	and something that may well be under-recognised by funding bodies if not clearly explained here) Thank you for taking into account these comments.	
Karen and Vicky, NCMD Comments received by email	**Page 3** - Care of baby and family - bullet point 4 - It would be good if they could include a link to this video https://vimeo.com/617024160 which we signpost to from our website. It is a video produced by SUDC-UK which explains the process of tissue sample collection, and provides advice to parents on making decisions. **Page 3** - Child death review - bullet point 4 - I think this sentence needs a minor edit. I understand why it has been phrased in the way it has to ensure that babies who are transferred to hospices for compassionate extubation are included in PMRT, but the way it is written at the moment suggests that well babies who die of SIDS at home, under 28 days, should also be reviewed via PMRT. PMRT is not the appropriate mechanism to review these deaths where a JAR is required. I therefore suggest the following edit - "..neonatal deaths in the first 28 days, except where a joint agency response is indicated, regardless of the location of death...." **Page 8** - 1-2 working days - Statutory / National Safety Notifications - bullet point 3 - The CDOP notification is now made via MBRRACE as the Cascade system links the two and supports automatic notification of CDOP. Therefore, suggest wording changes to "MBRRACE-UK (<48hrs England) which	Additional bullet point included. Modified to : “Neonatal units should use the Perinatal Mortality Review Tool (PMRT) to support the child death review meeting (CDRM) for all neonatal deaths in the first 28 days where neonatal care has been received, regardless of the location of death (can also be used for babies who die in neonatal units after 28 days). The JAR in itself does not mean the PMRT should not then be used to support the CDRM. We have also further clarified the position for deaths in other areas in the main body of the guidance. Modified to say • MBRRACE-UK – all UK (<48hrs Eng) & CDOP notification form (Eng) (SPEN/CASCADE system if ≤28 days old),

	makes onward notification to CDOP via the Cascade System, Child death notification form (Wales)	
	Page 8 - 1 week to 3 months - Staff Actions / Local investigation - bullet point 2 - include the word draft "CDOP draft analysis form and supplementary form completion and submission to CDOP office"	Added
	Page 8 - 1 week to 3 months - Statutory / National Safety Notifications - bullet point 3 - This should be moved to the box below so it is on the >3 months line. The CDOP review cannot take place until after the inquest and all other processes are completed. Suggest adding it to the current bullet point 3 in the >3 months box so the whole thing reads "CDOP review (England) including sending alerts of national relevance to NCMD."	Added
	Page 10 - Family support and communication - bullet point 4 - I think this needs slight re-wording as at the moment it reads as though parents would attend the CDRM. Suggest changing to "Contribution of families to the child death review meeting.." or otherwise an explicit statement is needed saying that families do not attend the meeting itself.	Modified to: The contribution of families to the Child Death Review Meeting (CDRM) improves dialogue and continuity of care between parent(s) and providers and empowers parent(s) to maintain a purposeful role following the death of their baby. The family key worker (bereavement midwife/neonatal nurse) should support the family to prepare questions/comments for submission to the CDRM. Families' views should be heard and questions answered at the CDRM.
	Page 11 - Table 2 - There is a typo in the heading of column 2. It should be CDR process	Thank you - altered
	Page 11 - Table 2 - I think JAR should be added to the local CDR process in row 2	JAR is included in the when required section

	Page 16 - England only - bullet point 1 - It would be helpful to add a couple of things here. Suggest changing to "For all deaths of liveborn infants, at any gestation, but not including legal terminations of pregnancy, even when liveborn"	Done
	Page 16 - England only - bullet point 4 - remove reference to NCMD. This should just read CDOP	Done
	Page 17 - Which babies should be reviewed? - There is a legal obligation for CDOPs to review all deaths of babies regardless of gestation so this para will need updating. Suggest replacing first para with - "There is a legal requirement to conduct a child death review for the deaths of all live born babies regardless of gestational age."	The statutory guidance for England is clearly outlined in the second paragraph.
Lydia Bowden On behalf of National Medical examiners office (Note: comments provided as notes directly on the guidance so have been pulled out of that document for this)	**Executive Summary** P4 - To develop a referral mechanism that allows the neonatal MCCD formulation on HMC referral and consider a neonate CN2 document P5 - Zoe and Ben are Regional MEs for England, not Wales. I cant see any representatives from the Welsh MES or the Welsh NHS / CDRT on the panel?	We do agree that development of neonatal specific documents would be helpful, both for medical examiner and coroner processes. However, we think this is beyond the scope of our document which is more targeted at neonatal clinicians. Apologies - there was discussion with various senior personnel involved in neonatal mortality governance within Wales outside of the working group during development.
	Introduction	The word faith removed.

	Not sure mention of faith reasons is necessary - parents may request this for other reasons and all should be considered. This should read "completion of MCCD by attending practitioner and independent scrutiny by medical examiner." I understand why ME discussion appears here as may not be sensitive in 1-2, however it should not be seen as permission to delay. A suggested amendment below. It should also say "England and Wales." "ME/MEO discussion with family if did not occur in days 1-2 (England and Wales)."	Added Added
	Care of Baby and Family P10 - This should read "...with the medical examiner or officer"	added
	Child Death Review - Immediate Decisions P11 - This is not quite correct, attending practitioner requirements changed in Sept 2024. "Final illness"" is not the requirement now, only that they attended the deceased ""in their lifetime" "attended in the last illness to write the MCCD." - It has now changed to 'attended in life' P12 - Medical examiners are required to have an interaction with the attending practitioner in all cases, current wording may lead readers to believe this is optional (the "interaction" can be by correspondence rather than verbal discussion) In England and Wales the completed MCCD is also sent directly to the register office from the ME	Modified. **Modified to:** In England and Wales, the proposed MCCD/case will then be scrutinised by a Medical Examiner (ME), with correspondence or verbal discussion between the ME and the attending physician.

	P13 - The discussion can be with a medical examiner officer. One way to say it might be "Offer the bereaved parents an opportunity to discuss the causes of death or any concerns with care with someone independent (the medical examiner or officer)."	Text modified. MEO included
	P14 – Re. Best practice recommendations for MCCD completion - perhaps highlight that in babies born with SoL after MTOP require HMC referral?	Added – it is also covered in the case examples.
	P15 – "within 5 for Eng" - within 5 days of the MCCD being sent to the register office "inform families that death registration will be delayed" - perhaps 'take longer' rather than 'be delayed'?	Text modified.
	P16 – "where HMC/PF referral is necessary there may be delays." - 'this may not be possible or arrangement may take longer' rather than delayed? "no formal decision can be made until the death has occurred." - In addition ME scrutiny of the records can not occur until after the death has occurred	Text modified Text modified.
	Appendix 2 – National Guidance P43 - The National Medical Examiner's guidance must be included for England and Wales. It is required by statute and MEs must follow it.	Added to the table

	https://www.england.nhs.uk/long-read/national-medical-examiners-guidance-for-england-and-wales/ P44 - In the example given, it is not clear why HMC referral is required (not listed as criteria in the Notification of Deaths Regulations) P45 - It would be better to use the published version of the flowchart (a link should be included or replace the diagram) https://www.england.nhs.uk/publication/national-medical-examiners-guidance-for-england-and-wales/#death-certification-reform P52 - As above, not clear in this example why HMC referral is required (not listed as criteria in the Notification of Deaths Regulations)	There are two reasons to refer: • A doctor is unable to write a MCCD if they have not treated the baby during their life. • Where there is uncertainty regarding whether a baby is born alive, these cases must be referred to the coroner (Chief Coroner's Guidance No.45 - Stillbirth, and live birth following termination of pregnancy. Changed to this version – thank you. As above.
Omer Aziz On behalf of National Paediatric Lead for Organ Donation, NHS Blood and Transplant	**Introduction** Table 1: Immediately after death row/ Staff Actions/Local Investigations column, it says Contact SNOD/TS re organ/tissue donation if eligible PRIOR to speaking to the family. Given that controlled organ donation is only possible in the UK, hence once death has been diagnosed then it would not be	

	possible to consider organ donation at that stage, hence contacting the SNODS would not be appropriate. Where as Tissue donation will still be possible and so I would suggest that this should read as: Contact Tissue donation Service re: tissue donation if eligible PRIOR to speaking to the family Whereas in the "Prior to death where anticipated" row the wording is appropriate.	We have removed SNOD/TS contact from immediately after death in line with other comments raised in the document.
	Any other comments Congratulations on producing this document and thank you for including Organ and Tissue Donation as a part of this.	Thank you.
Nick Lansdale on behalf of Neonatal Surgery Forum	In summary, the group felt the document was very helpful and well written. Given a significant proportion of deaths in the neonatal period are due to surgical conditions, we felt that involvement of a surgeon in the production of the framework may have been helpful. The key recommendation was that it should be explicit in the framework that when a baby has died and been affected by a surgical condition (having had an operation or not), the lead surgeon for that baby should be actively involved in the mortality review (CDR/PMRT). They may of course, also be involved in other processes e.g. family bereavement counselling or certification, depending on the case.	Thank you. We apologise that we did not involve a surgeon on the group and thank you for your comments.

	Some specific comments from individual members are as follows: ‘ The BAPM document is excellent. Something that comes up and is not explicit in this document nor the online statutory guidance is who should attend the CDRM. My view is that if a baby has a surgical condition then it would be best practice for a surgeon and ideally the named surgeon for that baby to attend the CDRM. I know all surgical depts have 'M&M' meetings or similarly named gatherings but I suspect learning from those does not feed often into the CDRM and PMRT. It would be best practice for this to happen I believe.’ ‘The BAPM document is very well written document - comprehensive, clear, nuanced and all relevant. There is not much specifically "surgical" other than recommendations for writing the death certificate - an operation should only be considered part of it (cause of death) if the surgery or a complication of it contributes more than minimally to a neonatal death. I doubt the document can make it clearer than that (but still leaves room for interpretation)’ ‘. It’s a useful, well written document and if a baby has a surgical condition implicated in any way with their death the (ideally named) surgeon should be involved (or at least offered the opportunity to be involved) with family bereavement follow	We have included an additional bullet point and expanded on this to specifically mention the lead surgeon. • Representation at CDRM should include all staff who participated in the baby’s care and the meeting should be open to all perinatal staff. All staff should feel able to contribute in a supported, non-judgemental environment. • Where mothers and/or babies have been transferred, it is vital that there is good communication and sharing of information across organisations and all teams involved in the care should be represented including relevant speciality input (e.g. surgery, transport, ambulance services). For surgical cases, the lead surgeon for the baby’s care should be actively involved in the mortality review. Thank you -now included in the statement above. We have expanded a little on this in the case study to try to give further explanation around this point. There will be a degree of interpretation required in this area. Added to the following bullet point in the family support and communication section

	up, review processes and if appropriate with what goes on the death certificate.'	• The named consultant should offer families the opportunity to meet to discuss ○ the results of the postmortem, and any outstanding investigations ○ the outcome and any actions following the CDRM ○ the outcome and any actions following any internal or external investigations Where another specialist team has been involved in the baby's care e.g. paediatric surgeon, the named surgeon may also wish to be involved in these discussions.

[i] Health and Social Care. Perinatal and Paediatric Pathology Services in Northern Ireland. [online] Perinatal Pathology N Ireland