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Independent Evaluation of the Pan London Lead Nurse for Neonatal Palliative Care Project: Evidence Supplement

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Annex A

Analysis of the cohort of babies who met the British Association of Perinatal Medicine eligibility for palliative care in 2014-2018, in the London Neonatal Operational Delivery Network

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Aims

We want to determine the incidence of babies who fulfil the categories for perinatal palliative care. This will provide an indication of the needs and palliative care resources necessary to support families.

The British Association of Perinatal Medicine (BAPM) drew up a framework for palliative care.¹ It suggested five categories of babies who may be considered for perinatal palliative care:

- Category 1: An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival, e.g. bilateral renal agenesis or anencephaly.
- Category 2: An antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death, e.g. severe bilateral hydronephrosis and impaired renal function.
- Category 3: Babies born at the margins of viability, where intensive care has been deemed inappropriate.
- Category 4: Postnatal clinical conditions with a high risk of severe impairment of quality of life and when the baby is receiving life support or may at some point require life support, e.g. severe hypoxic ischemic encephalopathy.
- Category 5: Postnatal conditions which result in the baby experiencing “unbearable suffering” in the course of their illness or treatment, e.g. severe necrotizing enterocolitis, where palliative care is in the baby’s best interests.

The aim of this analysis is to establish the cohort of babies in the London Neonatal Operational Delivery Network (ODN) who met the BAPM eligibility for palliative care in the five years from 2014 to 2018, using the BAPM categories.

Methods

There is no agreed list of diagnoses or conditions for each of the BAPM categories, so it was necessary to make an initial judgment as to which were relevant, for the purposes of this analysis.² We recommend further work through a stakeholder group to develop a consensus decision as to which specific conditions fulfil the BAPM categories 1-5.³

¹ BAPM (2010) *Palliative Care: A Framework for Clinical Practice in Perinatal Medicine* <https://www.bapm.org/resources/30-palliative-care-a-framework-for-clinical-practice-in-perinatal-medicine-2010>.

² As outlined below, with further detail in the supplementary tables at the end of this Annex.

³ See recommendations i-ii at the end of this article.

Data was extracted centrally from the National Neonatal Research Database (NNRD) by the Neonatal Data Analysis Unit. We extracted data for babies of all gestational ages admitted to neonatal care in the London Neonatal ODN during 2014 to 2018 inclusive.

The NNRD holds appropriate Confidential Advisory Group (CAG) approval. Specific ethics approval was not sought for this study as it was viewed as service evaluation. Permissions were provided through a letter from the London Neonatal ODN to the Clinical Leads of all London's neonatal units.⁴

Daily and episodic data variables were extracted to address the following:

- Determine proportion of babies with conditions that fulfil BAPM categories of care 1 (not compatible with long-term survival) and 2 (high risk of morbidity or death).
- Category 3: Babies born less than 23 weeks gestation.
- Category 4: Severe impairment of quality of life. Hypoxic ischaemic encephalopathy: Brain injuries as defined by severe HIE grade 3, IVH grade 3 and 4, Kernicterus, Periventricular leukomalacia. We also looked at babies who had a tracheostomy/gastrostomy and Ventriculoperitoneal shunt as these indicated the need for ongoing support.
- Category 5: This is hard to define as not all severe NEC is an indication for palliative care. We chose a length of stay cut-off, in that any baby still on the unit at 44 weeks post menstrual age is likely to have complex needs.
- Proportion of these babies that fulfil BAPM categories 1-5 that died in the neonatal unit, discharged home, discharged to another hospital or ward.

Results

During a five-year period of 2014-2018 inclusive, 59,780 babies of all gestational ages were admitted to neonatal units in London (defined as at least one day cared for on the neonatal unit).

- 43 babies fulfilled BAPM category 1 (not compatible with long-term survival).
- 1,391 for category 2 (high risk of significant morbidity or death).
- 6 for category 3 (limits of viability; we defined this as born less than 23 weeks) – please note these are babies admitted to the neonatal unit only.
- 1,293 babies fulfilled BAPM category 4 (high risk of severe impairment of quality of life and requiring ongoing support). These include 1,000 babies having recorded brain injuries, and 169, 84, 86 babies with a tracheostomy, gastrostomy, ventriculo-peritoneal shunt, respectively, at some point during their admission.
- 1,422 babies fulfilled BAPM category 5 ('unbearable suffering'; we used a proxy for complexity - preterm and term babies who were in-patients at 44 weeks postmenstrual age) (see Table 1).

The proportion of babies who died in NNU was 40%, 10%, 50%, 17%, 4% for those fulfilling BAPM categories 1-5 respectively. The proportion of babies discharged home was 40%, 46%, 33%, 65% and 69% for BAPM categories 1-5 respectively.

The missing data was largely due to the April 2019 data download used, and hence some care episodes for babies born in 2018 were incomplete. This would be mitigated in a larger, more comprehensive study using the most recent download.

⁴ Letter to Clinical Leads of all London Neonatal providers from the London Neonatal ODN Network Director and Pan London Lead Neonatal Nurse, 20 December 2018.

Discussion

We conducted a retrospective analysis for London units using data held on the NNRD. BAPM does not specify the conditions or circumstances included in each category. For example, there is no consensus list of diagnoses in the literature regarding which conditions are not compatible with long-term survival (category 1) or 'unbearable suffering' (category 5). With advances in medical care and provision of community support, an increasing number of babies with conditions previously considered lethal are now surviving for longer.

This study was intended as a preliminary scoping exercise to examine the feasibility of using NNRD to quantify the population of babies who would benefit from palliative care support. For the purposes of this study, we therefore set up definitions for each category *a priori*, accepting that these by no means represent the granularity necessary. We identified variables held on the NNRD that could be used as a proxy to represent complex and palliative care needs.

Over 4,000, or 7%, of all babies admitted to neonatal care in 2014-2018 fulfilled BAPM categories 1-5 for palliative care. Importantly, many of these babies with complex needs are discharged home, suggesting that there would be a need for support in the community.

The highest NNU mortality was among those in BAPM category 3 (less than 23 weeks), although numbers are small. Even for those babies in category 1, deemed not to survive in the long-term, 40% are being discharged home. Around 65-70% of those babies who are likely to have impaired quality of life are also being discharged from neonatal care.

This is the first study to quantify palliative care needs across a region using an established database that captures all admissions to neonatal care. We have demonstrated that it is feasible to use the NNRD to identify babies with complex needs and suggest a more comprehensive study is necessary to confirm these findings. There are several considerations, if a larger national and more comprehensive study was to be undertaken:

- i. We recommend that a consensus decision be made regarding which specific conditions would fulfil BAPM categories 1-5; this is necessary for the data extraction from NNRD and category assignment.
- ii. We suggest involvement of a wide stakeholder group including Neonatal health professionals, hospices, palliative care teams and parents. For example, consensus opinion about what conditions would be a proxy for 'severe impaired quality of life' or 'unbearable suffering' for BAPM categories 4 and 5.
- iii. We recommend that the neonatal electronic patient record (EPR) separates hospice from hospital in the discharge destination. Currently the term on the EPR is "Discharge to hospital or hospice". We have put forward this suggestion for the Neonatal Dataset revision. It was therefore very difficult to quantify the number of babies discharged to hospices.
- iv. Finally, we recommend new data items to be added to the Neonatal Dataset to capture whether the baby was identified as having palliative care needs; which BAPM category; whether a plan has been made with the parents; whether the baby had a palliative or end of life care plan in place at the time of discharge.

Conclusions

In the last five years, around 4,000 (7%) of babies with complex care needs and high risk of morbidity and mortality were cared for in neonatal units in London. Many of these babies are discharged from neonatal care, suggesting that there is ongoing need for support in the community.

We have demonstrated the utility of the NNRD to help quantify the resource needs of this complex population, and recommend a national and more comprehensive study to be undertaken to confirm these findings and ensure they are generalisable to other regions. We have also put forward recommendations to introduce new data items to the Neonatal Dataset that would capture more granular information regarding palliative care plans and discussions with parents whilst in the neonatal unit.

Data and supplementary tables are shown on the following pages.

Table 1: Number of babies who fulfilled BAPM category 1-5

(Codes used for categories 1 and 2 are shown in the supplementary tables at the end of this annex)

	2014	2015	2016	2017	2018	Total
Total admissions	11603	12371	12300	12184	11322	59 780
BAPM category 1	10	11	8	5	8	43
BAPM category 2	297	319	290	270	215	1391
BAPM category 3	0	1	2	2	1	6
BAPM category 4*	255	272	304	252	210	1293
Total (Brain injuries or procedures that indicate ongoing support required)						
All brain injuries total babies	<i>178</i>	<i>201</i>	<i>243</i>	<i>196</i>	<i>182</i>	<i>1000</i>
<i>Severe HIE grade 3</i>	<i>73</i>	<i>67</i>	<i>77</i>	<i>86</i>	<i>57</i>	<i>360</i>
<i>Injury</i>	<i>15</i>	<i>23</i>	<i>23</i>	<i>21</i>	<i>35</i>	<i>117</i>
<i>CNS infection</i>	<i>21</i>	<i>19</i>	<i>25</i>	<i>20</i>	<i>19</i>	<i>104</i>
<i>Kernicterus</i>	<i>0</i>	<i>1</i>	<i>2</i>	<i>0</i>	<i>2</i>	<i>5</i>
<i>Grade 3 or 4 IVH</i>	<i>48</i>	<i>69</i>	<i>90</i>	<i>57</i>	<i>54</i>	<i>318</i>
Periventricular leukomalacia	27	34	41	28	23	153
Procedures that indicate ongoing support required						
Tracheostomy at any time	37	40	42	29	21	169
Gastrostomy at any time	21	21	18	19	5	84
VP shunt at any time	30	22	13	14	7	86
BAPM category 5 not mutually exclusive total						
Any preterm <37 weeks baby still an inpatient at postmenstrual age of 44 weeks	170	163	141	149	107	730
Any term baby still an inpatient at 44 weeks PMA	150	127	141	157	117	692

* The babies in each BAPM 1, 2, 3 category are mutually exclusive, but category 4 and 5 babies can be in more than one group i.e. double counting.

Table 2: Discharge/death outcomes for babies in BAPM categories 1-5

BAPM category	Died in NNU	Discharged home	Discharged from neonatal care to another ward or hospital	Discharged to postnatal or transitional care ward	Discharged from neonatal care to another ward or hospital	Missing
1. n=43	17 (39.5%)	17 (39.5%)	8 (18.6%)	1 (0.02%)	8 (18.6%)	0
2. n=1391	140 (10.1%)	635 (45.7%)	512 (36.8%)	100 (7.2%)	512 (36.8%)	4 (0.3%)
3. n=6	3 (50%)	2 (33.3%)	0	0	0	1 (16.7%)
4. n=1293	222 (17.2%)	841 (65.0%)	149 (11.5%)	68 (5.3%)	149 (11.5%)	13 (1.0%)
5. n=1422	62 (4.4%)	985 (69.2%)	343 (24.1%)	4 (0.3%)	343 (24.1%)	28 (2.0%)

Supplementary tables

BAPM category 1. An antenatal or postnatal diagnosis of a condition which is not compatible with long term survival, e.g. bilateral renal agenesis or anencephaly.

15890	Anencephaly
16475	Thanatophoric short stature
15918	Holoprosencephaly
16594	Trisomy 18, meiotic nondisjunction
16595	Trisomy 18, mosaicism (mitotic nondisjunction)
16597	Edwards syndrome (unknown or unspecified cause)
16598	Trisomy 13, meiotic nondisjunction
16599	Trisomy 13, mosaicism (mitotic nondisjunction)
16601	Patau's syndrome (unknown or unspecified cause)
16602	Edwards syndrome and Patau's syndrome
200100	Lethal or life-threatening birth defect not listed elsewhere
200902	Other lethal or life-threatening congenital heart defects not listed elsewhere
500252	Other lethal or life-threatening pulmonary malformations
16036	Ventricle single
16318	Renal agenesis, bilateral
500250	Tracheal agenesis or atresia
1010778	Laryngeal Atresia
15893	Anencephaly and similar malformations
200904	Other lethal or life-threatening genito-urinary defects not listed
200903	Other lethal or life-threatening gastro-intestinal defects not listed elsewhere

BAPM category 2. An antenatal or postnatal diagnosis of a condition which carries a high risk of significant morbidity or death, e.g. severe bilateral hydronephrosis and impaired renal function.

15891	Craniorachischisis
15892	Iniencephaly
15894	Frontal encephalocele
15895	Nasofrontal encephalocele
15896	Occipital encephalocele
15897	Encephalocele of other sites

15898	Encephalocele (unknown or unspecified cause)
15899	Encephalocele
15918	Holoprosencephaly
15926	Cervical spina bifida with hydrocephalus
15927	Thoracic spina bifida with hydrocephalus
15928	Lumbar spina bifida with hydrocephalus
15929	Sacral spina bifida with hydrocephalus
15930	(unknown or unspecified cause) spina bifida with hydrocephalus
15931	Cervical spina bifida without hydrocephalus
15932	Thoracic spina bifida without hydrocephalus
15933	Lumbar spina bifida without hydrocephalus
15934	Sacral spina bifida without hydrocephalus
15935	Spina bifida (unknown or unspecified cause)
10986	Spina bifida
10704	Myelomeningocele (specify site)
15936	Spina bifida
10356	Double outlet right ventricle (DORV)
16025	Double outlet right ventricle (DORV)
16026	Double outlet left ventricle (DOLV)
16028	Double inlet ventricle (DILV)
16032	Cong malforms of cardiac chambers and connections unspec
16033	Congenital malformations of cardiac chambers and connections
16045	Pulmonary valve atresia
16048	Other congenital malformations of pulmonary valve
16049	Congenital tricuspid atresia / stenosis
16050	Ebstein's anomaly
16051	Hypoplastic right heart syndrome
16052	Other congenital malformations of tricuspid valve
16053	Congenital malformation of tricuspid valve (unknown or unspecified cause)
16058	Mitral atresia
16059	Hypoplastic left heart syndrome (HLH)
16082	Malformation of aorta
16083	Atresia of pulmonary artery

11057	Total anomalous pulmonary venous drainage (TAPVD)
16092	Total anomalous pulmonary venous connection (TAPVD)
10123	Bilateral renal agenesis
16318	Renal agenesis, bilateral
16324	Potter's syndrome
16327	Polycystic kidney, infantile type
10100	Autosomal recessive polycystic kidney - infantile
16360	Congenital absence of bladder and urethra
10008	Absence of bladder
10236	Congenital absence of urethra
10246	Congenital diaphragmatic hernia
10490	Hernia into the cord
16495	Congenital diaphragmatic hernia
16496	Aplasia of diaphragm
16497	Eventration of diaphragm
16589	Trisomy 21, meiotic nondisjunction
16590	Trisomy 21, mosaicism (mitotic nondisjunction)
16591	Trisomy 21, translocation
16592	Down's syndrome (unknown or unspecified cause)
16593	Down's syndrome
200102	Meningomyelocele
200606	Myotonic dystrophy requiring endotracheal intubation and assisted ventilation
15180	Werdnig-Hoffman - SMA type 1
15181	Spinal Muscular Atrophy
15182	Basal ganglion calcification
15183	Basal ganglion cyst (s)
15184	Cerebral atrophy - after meningitis
15186	Complex partial seizures
15199	Muscular dystrophy
15200	Myotonic Dystrophy
15201	Myotonic disorder
15202	Congenital myopathy
15203	Mitochondrial myopathy

15205	Cerebral Palsy - dyskinetic
15207	Cerebral palsy - mixed
15916	Congenital malformations of corpus callosum
15919	Other reduction deformities of brain
15920	Septo-optic dysplasia
15921	Megalencephaly
15922	Congenital cerebral cysts
15923	Other specified congenital malformations of brain
15924	Congenital malformation of brain (unknown or unspecified cause)
15925	Other congenital malformations of brain
15938	Hypoplasia and dysplasia of spinal cord
15942	Other specified congenital malformations of spinal cord
15943	Congenital malformation of spinal cord (unknown or unspecified cause)
15944	Other congenital malformations of spinal cord
15946	Arnold-Chiari syndrome
15947	Other specified congenital malformations of nervous system
15948	Congenital malformation of nervous system (unknown or unspecified cause)
15949	Other congenital malformations of nervous system
16134	Congenital malformation of larynx (unknown or unspecified cause)
16135	Congenital malformations of larynx
16138	Other congenital malformations of trachea
16139	Bronchomalacia
16140	Congenital stenosis of bronchus
16141	Congenital malformations of bronchus
16142	Congenital malformations of trachea and bronchus
16151	Agenesis of lung
16577	Zelweggers syndrome
16583	Conjoined twins
16603	Whole chromosome trisomy, meiotic nondisjunction
16604	Whole chromosome trisomy, mosaicism (mitotic nondisjunction)
16605	Major partial trisomy
16608	Duplications with other complex rearrangements

16609	Extra marker chromosomes
16610	Triploidy and polyploidy
16611	Other specified trisomies and partial trisomies of autosomes
16612	Trisomy and partial trisomy of autosomes (unknown or unspecified cause)
16613	Other trisomies and partial trisomies of the autosomes
16616	Chromosome replaced with ring or dicentric
16617	Deletion of short arm of chromosome 4
16618	Deletion of short arm of chromosome 5
16619	Other deletions of part of a chromosome
16621	Deletions with other complex rearrangements
200605	Inborn error of metabolism (unspecified)
200606	Myotonic dystrophy requiring endotracheal intubation and assisted ventilation
200102	Meningomyelocele

Annex B

Study Days: Education and Training outcomes

1. Evidence used in this analysis
2. Education and training outcomes
 - 2.1 Meeting expectations and learning outcomes achieved
 - 2.2 Making referrals to palliative care services
 - 2.3 Improved equity, choice and care for families
 - 2.4 Embedding palliative care approaches in neonatal units
3. Future learning needs

1. Evidence used in this analysis

Participants at the neonatal unit Study Days were asked to fill in detailed paper questionnaires, before and after the training. These were entered into Excel for analysis, with key data reported to the project steering group at regular intervals. In all:

- 319 pre-training questionnaires were collected at 24 Study Days between October 2015 and May 2017
- 464 post-training questionnaires were collected at 32 Study Days between July 2015 and May 2018.

Questionnaires were completed anonymously. Unfortunately, pre- and post-training data cannot be linked, but it is possible to infer impact by comparing responses to questions included in both questionnaires.

The early hospice-based Study Days were evaluated using a variety of forms (reflecting each hospice's preferred approach) before a standard form was adopted from November 2016. The hospice Study Day data available to this evaluation includes:

- 57 non-standard feedback forms collected at 3 hospice Study Days (March 2015 to October 2016)
- 107 standard feedback forms collected at 7 hospice Study Days (November 2016 to April 2018).

In addition to the extensive questionnaire data collected on the Study Days, two other methods were used to evaluate education and training outcomes:

- A 'nominal group evaluation' was held in June 2017, involving eight senior nurses (designated leads for palliative care) from across the London Neonatal ODN. This used a structured focus group to explore the strengths and challenges of the project, capturing everyone's ideas and using group discussion and voting to prioritise them.
- A short online survey (using SurveyMonkey) to gather evidence of impact in the later stages of the programme, between October 2017 and July 2018. This was emailed to Study Day participants at least one month after the Study Day, with 32 responses received.

2. Education and training outcomes

2.1 Meeting expectations and learning outcomes achieved

The Study Days were rated very highly. When asked ‘How far did the Study Day meet your expectations?’, participants on hospital-based Study Days between 2015-2018 (n=463):

- 89% answered ‘completely’
- 11% answered ‘somewhat’
- No-one answered ‘not at all’.

They were also asked to rate each of the learning sessions on the Study Days. The question format varied, with very positive results throughout. Focusing first on the largest sample (335 participants on Study Days in 2015-2016):

- 80% of participants said the sessions met their learning needs ‘completely’
- 19% answered ‘somewhat’
- <1% (4 out of 2,000) learning sessions were rated negatively (‘not at all’).

The highest-rated session (84% ‘completely’) was on ‘resources to enhance palliative care provision’, while the lowest rated session was on ‘insight into parents’ information needs’ (78% ‘completely’). The table below provides a breakdown of learning outcomes:

Reflecting on your learning this morning, to what extent did the session provide:	Not at all	Somewhat	Completely
Resources to enhance palliative care provision	0%	16%	84% highest
Information about palliative care relevant to your practice	0%	17%	82%
Additional knowledge on the potential for antenatal palliative care	0%	20%	80%
New learning about palliative care for babies receiving palliative care	0%	21%	79%
Insight into the potential for integrating palliative care in the neonatal environment	1%	20%	79%
Insight into parents' information needs	0%	22%	78% lowest

A slightly different question was used in 2017-18. When asked ‘reflecting on the sessions today, to what extent did they contribute to your knowledge?’ (N=128 Study Days participants, 2017-2018):

- 85% answered ‘completely’
- 15% answered ‘somewhat’
- No learning sessions were rated negatively.

Ratings for individual sessions ranged from 91% to 74% ‘completely’ meeting learning needs, as shown in the table below:

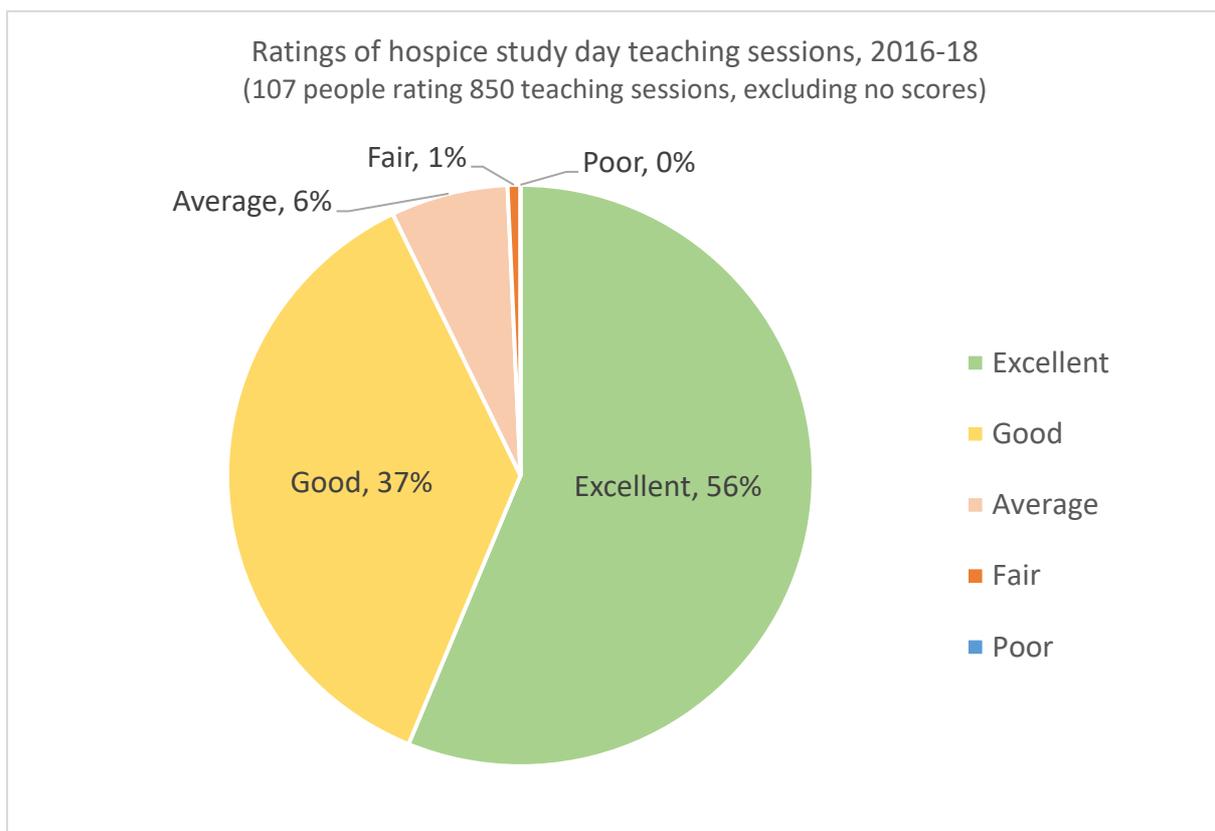
Learning outcomes reported	Not at all	Somewhat	Completely
Improved understanding of the principles in neonatal palliative care	0%	9%	91% (highest)

Improved understanding of what services and resources are available to families and how to access them, enabling equity of choice for families	0%	9%	91%
Improved understanding of the collaboration across local services for consistent high quality care	0%	13%	88%
Improved understanding of how to apply those principles & philosophy of care within an acute neonatal setting	0%	20%	80%
Practical guidance for the management of palliative care on neonatal units, including new development such as organ donation for infants	0%	25%	74% (lowest)

N=128 Study Day participants, 2017-2018. Figures rounded to nearest whole % point.

Participants on hospice-based Study Days were also asked to report on learning outcomes, on a five-point scale from 'excellent' to 'poor'.

Outcomes from the largest sample (N=107 participants on hospice Study Days between 2016-2018) are shown in the chart below: this shows that 93% learning sessions were rated 'excellent' or 'good' with only 7% rated 'average' or 'fair'. No session was rated as 'poor'.



Data was available from a further three hospice Study Days, which used different questions. Headline results from these are:

- 100% (N=34) of respondents indicated that their ‘knowledge had improved’ at two Study Days in 2015 and 2016, where simple ‘yes/no’ options were offered
- 23 participants at a Study Day in 2016 awarded an average score of 4.7 out of 5 in terms of their overall rating of the day, with no score below 4.

2.2 Making referrals to palliative care services

Participants on the hospital-based Study Days were asked about their confidence in making referrals to a range of palliative care services. Options listed were a children’s hospice, (named) hospital palliative care teams, a community-based palliative care team, or a community children’s nursing service – these were aggregated for analysis.

Comparing their answers before and after training provides clear evidence that the Study Days increased participants’ confidence in making such referrals, as shown in the table below. In brief:

- Those feeling ‘not confident’ fell by 42 percentage points as a result of the training, from one in every two participants (52%) pre-training, to one in ten (10%) post-training
- Those feeling ‘confident’ increased by 40 percentage points, from around one quarter (27%) of participants pre-training, to two-thirds (67%) post-training
- Those feeling ‘very confident’ increased by 11 percentage points, from 4% pre-training to 15% post-training.

How confident do you feel making a referral to palliative care services?

RESPONSES	NOT CONFIDENT	CONFIDENT	VERY CONFIDENT	N/A
Pre-training (N=265)	52%	27%	4%	17%
Post-training (N=330)	10%	67%	15%	8%

Survey responses from 24 Study Days in 2015-2016.

The question format changed in early 2017, when different questions and scales were used in the pre- and post-training questionnaires. On three (of eight) Study Days during this period, ‘n/a’ and/or ‘unsure’ options were not offered in the post-training questionnaires, which may have influenced responses, so caution is due in comparing outcomes.

Nonetheless, the proportion of participants reporting that they felt confident about making a referral to palliative care services having completed the training (83% in 2017), was almost identical to that in the earlier questionnaires (82% confident or very confident in 2015-2016 questionnaires). Aggregated results are shown below:

<i>Do you have an understanding of the process in making a referral to palliative care services?</i>				
Pre-Training N=54	N/A	Not at All	Somewhat	Good Understanding
	9%	53%	32%	5%
<i>How confident do you feel making a referral to palliative care services? (NB no/fewer neutral options used on some days)</i>				
Post-Training N=129	N/A	No	Unsure	Yes
	5%	2%	10%	83%

Survey responses to 8 Study Days in 2017.

2.3 Improved equity, choice and care for families

Two of the top strengths of the Pan London Neonatal Palliative Care Project, identified in a structured focus group of lead nurses from across the London Neonatal ODN (June 2017), were:

- Improved provision of choice for families with end of life care decisions, such as transfer to a hospice, referrals to a hospice for family support, first experience of exploring organ donation
- Improved parent and family experience e.g. reducing stress for the family and empowering them with information, knowledge, and skills to make informed decisions.

Analysis of the post-training questionnaires and the online follow-up questionnaire indicates that many participants felt the training equipped them to offer improved equity, choice and care for families whose babies have palliative care needs. This was associated with two positive outcomes which emerged consistently from the evidence, namely:

- Improved knowledge of palliative care and the services available to support families
- Increased confidence in caring for babies with palliative care needs and their families.

Improved knowledge of palliative care and the services available to support families

The post-training questionnaire in 2017/18 (but not earlier versions) asked how far the Study Day contributed to 'Improved understanding of what services and resources are available to families and how to access them, enabling equity of choice for families.' 91% of respondents (N=128) answered 'completely', making this the joint highest rated learning outcome; alongside 'improved understanding of the principles in neonatal palliative care', which was rated equally highly.

Post-training questionnaires (2015-2018) sought feedback from participants who had previously attended similar training, on how it had influenced their practice. Only 7% of participants (N=34) indicated that they had attended such training before and explained in their own words how it had influenced their own practice. The most common theme to emerge (12 responses) was that it improved their knowledge of palliative care and the services available to support families, for example:

I have more information as to the support and resources available. I have a clearer picture of how the process takes place and know who to contact and give me some confidence as to how to deal with similar situations in the future.

Awareness of all services available in the community

More aware of hospice care and what is possible

Several said that this enabled them to discuss options and make referrals sooner (four responses) for example:

Yes, more earlier referrals

Yes, not to leave support 'til the end

More use of palliative care/ hospice support in the last few years

In addition to learning about dedicated palliative care services, another post-training survey question showed that participants valued the knowledge they gained on wider services to support families, particularly Remember My Baby (photography) and the Rainbow Trust:

*Remember my baby - amazing service
I was not aware of the Rainbow Trust. This will be very useful to our families on the unit.*

Increased confidence in caring for babies with palliative care needs and their families

The online follow-up survey asked if people who had attended the training had 'increased confidence in caring for babies with complex and palliative needs and their families, following the training day'. 26 out of 28 respondents answered yes, 2 answered no (with no insights offered).

24 of those who had gained in confidence following the Study Day provided information to explain their answer. The most common reason (10 responses) related to their improved knowledge and understanding of resources and services to support families (as above):

*Knowing the various services available for our babies and their families has made me more confident
More aware of what is available and feel more confident discussing options with parents
Able to talk confidently about what the hospice can offer*

Gaining knowledge of palliative care guidelines, processes and policies also helped to increase confidence (4 responses), for example:

*Yes, I know where to find comprehensive guidelines
Understand more about the processes to help these families*

Two people felt the training helped them in dealing with sensitive discussions:

*Breaking bad news
It has been helpful to hear about discussions that neonatologists are having with parents and parents' interpretations about what is being said.*

Lastly, two simply stated that they felt more confident in supporting families, in line with the positive answer they'd already given:

*I feel more confident in looking after the whole family.
I am more confident in talking with families and supporting them to get involved in their babies' care.*

2.4 Embedding palliative care approaches in neonatal units

Study Day participants reported a wide variety of ways in which they had put their knowledge into practice in their neonatal unit since the training. These included:

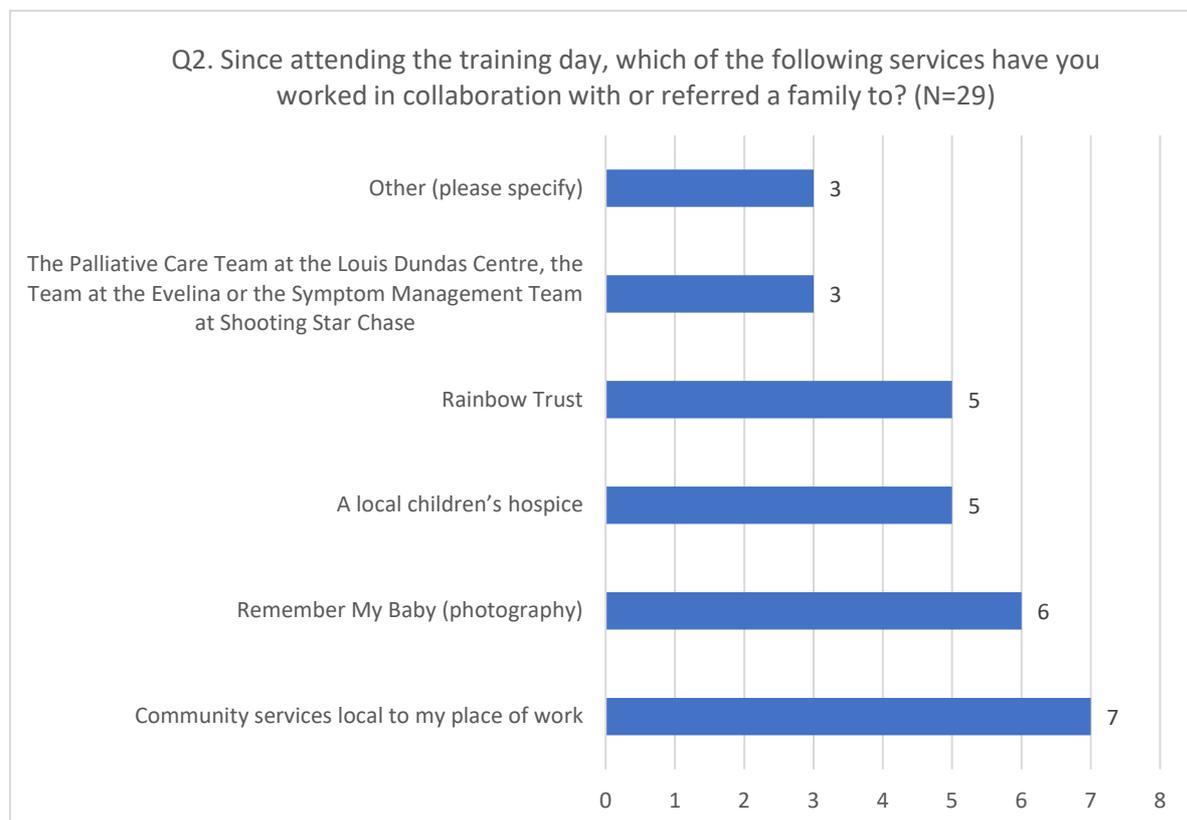
- 2.4.1 Multi-disciplinary working
- 2.4.2 Pathways and/or guidelines
- 2.4.3 Sharing learning with colleagues, developing practical resources
- 2.4.4 Psychological support

2.4.1 Multi-disciplinary working

The nominal group evaluation (structured focus group of lead nurses, June 2017) identified ‘Networking within hospital and external services - Midwifery & Paediatrics, Rainbow Trust Charitable organisations, Siblings group’ as one of the top strengths of the programme.

Consistent with this, ‘Improved understanding of the collaboration across local services for consistent high quality care’ was a highly-rated learning outcome in the 2017-18 post-training questionnaires (not included in earlier versions), with 88% of respondents feeling that the training achieved this ‘completely’.

The online follow-up survey conducted towards the end of this project provides further evidence of a positive influence on collaborative working. Out of the 29 respondents (who had all attended Study Days), 27 indicated that they had worked with or referred a family to a range of palliative care services, as shown in the chart below. One commented: “*The study day highlighted how we need to network more closely together to get the care right for the babies and their families*”. The other two respondents said that this was ‘not applicable’ in their current role.



Note: Respondents were able to select one of these options. We received the following answers for ‘Other’: “We have looked at ALL these options...of huge benefit.” (1); “None so far, not working clinically full-time.” (1); and “N/A” (1).

2.4.2 Pathways and/or guidelines

A healthcare guideline provides evidence-based advice and recommendations to promote consistent, high quality approaches to care.⁵ A pathway means a clearly-defined route from the time of diagnosis (or other significant point) to referral to appropriate services, provision of care and so on.⁶ This term is sometimes used more loosely to describe a working plan of what is expected to happen, setting out options for care at key stages in a patient's journey.

The follow-up online survey asked if people who had been on a Study Day had embedded aspects of the training into routine neonatal care; four options were offered, and one could be selected. The survey received 32 responses, 2 of which indicated that they had not implemented any of these options (one due to current role, one as all these elements were already in place).

Nearly one-third of respondents (10 of 32) selected 'development of local guidelines or pathways' as the option implemented in their neonatal unit. The audit conducted for this evaluation of neonatal units across London indicates that most now have a specific local guideline or framework in place for delivering neonatal palliative care.⁷

Similarly, the structured focus group of lead nurses (June 2017) noted that one of the strengths of the programme was its contribution towards "Increased standards of care in Neonatal Complex and Palliative care", attributable to several factors, including "Striving to meet written standards, which are now available."

2.4.3 Sharing learning with colleagues, developing practical resources

34 Study Day participants who had attended a similar training session several years ago provided details on how their practice had since changed. Of these, five described how they had shared learning and information with colleagues or developed practical resources for colleagues and families. For example:

Support to teams/network whenever an opportunity to disseminate information through different networks/clinical presentation

Will make our services better as currently re-doing our folders, forms, memory boxes (memory boxes were also mentioned by another respondent)

The main thing is helping to educate the doctors that [it] is okay to provide palliative care

2.4.4 Psychological support

The follow-up online survey asked respondents for examples of development or innovations in practice which they had initiated, following the Study Day. Nineteen examples were provided, four of which related to improving psychological support for staff:

We now have a unit psychotherapist

Understanding compassion fatigue

We have asked for a copy of the debriefing framework so that we can incorporate it in to our practice.

⁵ For example, Mancini A. et al (2014) [Practical guidance for the management of palliative care on neonatal units](#), RCPCH and Chelsea and Westminster Hospital NHS Foundation Trust

⁶ For example, TfSL (2016) [Perinatal Pathway for Babies with Palliative Care Needs](#).

⁷ See Standard 3: Guidelines/framework, Annex C.

Using the palliative team to help to direct pre-debrief discussion with staff was beneficial to all involved, it also helped to inform our practice on the unit.

This emerged as an area for development in around one-fifth of neonatal units in London, in the audit conducted for this evaluation in Summer 2019.⁸

3. Future learning needs

The post-training questionnaires until early 2017 explored future learning needs by asking participants to rate their 'information needs', with six options. 'Free text' responses (i.e. in their own words) were also sought in all the post-training questionnaires, asking what people would like to learn more about.

The table below shows how participants on Study Days between 2015-2017 rated the six learning options listed. Their answers have been weighted and aggregated to provide a ranked list of learning priorities.

The top two priorities involve sensitive discussions with parents, around prognosis and options for care and treatment; the bottom two involve making referrals, perhaps because this was already well covered in the training.

What would you like to learn more about? <i>Rate your information needs as low, medium or high.</i>	Weighted scores (low=1, med=2, high=3)			
	Low	Medium	High	TOTAL
Discussing with parents a prognosis that includes expectation of death or severe disability	22	236	513	771
Discussing with parents the options for care and treatment	25	260	477	762
Management of the signs and symptoms of a baby with a life-threatening or life limiting condition	44	292	360	696
Utilising the services of the (consultant-led) palliative care teams	59	304	303	666
Making a referral to a community based palliative care team	68	320	246	634
Making a referral to a children's hospice	81	316	219	616

N=335 post training surveys. Note: 6-7% of respondents selected ' n/a' to each of the options. These responses were not included in this weighted analysis.

All the surveys (2015-2018) included a free text question on what people would like to learn more about, although only a minority of participants responded. Answers were analysed thematically and are summarised in the table below.

There is much congruence between the two types of responses; notably, sensitive conversations with parents emerge as a priority in both. All six options consulted on (see table above) were also reflected in the free text answers. Other top themes to emerge include (in order of frequency):

⁸ See Annex C, Standard 10: Staff support.

- Organ donation (12 mentions)
- Knowledge of hospice services and referrals (11 mentions)
- End of life care (9 mentions)
- Caring for a baby who has died on the unit and their family (9 mentions)
- More parents' experiences, and more case studies (7 mentions each).

Theme and no. of responses (in order of frequency)	Illustrative quotes
Organ donation (12)	<i>Neonatal organ donation Process of organ donation</i>
Knowledge of hospice services and referrals (11)	<i>I would like to visit hospices to improve my knowledge and become more informed when referring patients. What medical care can hospices provide e.g. ventilation, infusions?</i>
Talking to parents about palliative care/bad news (10)	<i>Communicating with families in difficult conversations Practical guidance on how to introduce the concepts of palliative care with families, particularly when the diagnosis/prognosis is uncertain Role-playing how to cope with these situations.</i>
Knowledge of how the palliative care team works and symptom management (10)	<i>More in-depth knowledge of how the palliative care team works Talk from GOSH about their services I would like to learn more about managing babies' symptoms and medication</i>
End of life care (9)	<i>What end of life in the community for babies is like? In unit end of life care The process of withdrawing care Parental involvement in end of life DNA/CPR</i>
Caring for a baby who has died in the unit and their family (9)	<i>Caring for babies after death e.g. cares, dressing, washes Cold cots / Cold room practicalities Local practical elements e.g. registering death, funeral, post mortem procedure. Transfer of body home - legal requirements</i>
Parents' experience (7)	<i>Parents' view – what is helpful, what they found best to say to them? Videos</i>
More case studies (7)	<i>I would like to have more scenarios and reflexion within the professionals. Share more experiences about how nurses deal in this situation or stories/examples about palliative care. Get rid of the slides and just talk about examples!</i>
On-going care for complex babies and families (5)	<i>What other facilities are in the community for parents, like the Rainbow Trust? How to refer to nursing services for baby with complex needs that may live for months/years</i>
After-care for parents and staff, including bereavement care (4)	<i>What happened with the family afterwards? Do they cope better with the loss of their baby, after being well supported by the hospice team? What about the staff? How do they feel after loss? Bereavement care for care providers</i>
Referrals (generally, unspecified) (4)	<i>Who can make referral - Can it be a nurse/MDT? Where are referral forms available?</i>

<p>Incorporating into NICU incl. information needs (4)</p>	<p><i>With limited facilities in a unit, what little things can provide that are proven to help?</i> <i>How can incorporate more of palliative care into everyday activities, i.e. focus more appropriate strategies within more integrated ways of working?</i> <i>How to find all the information, trust policies, guidelines?</i></p>
<p>Other (5)</p>	<p><i>Need <u>experience</u> of palliative care with hospitals, community, hospices etc – at least we could see these places.</i> <i>Integrating maternity, the facilitator needs to encourage more integration of everyone!</i> <i>Mortuary visit</i> <i>Learning from abroad (palliative care)</i> <i>How to join in fund-raising programmes</i></p>

Annex C

Audit of neonatal palliative care across the London Neonatal ODN

1. Regional context
2. How the audit was conducted and limitations
3. Audit findings reported against each standard

1. Regional context

There are currently 10 Neonatal Operational Delivery Networks (ODNs) commissioned by NHS England's Specialised Commissioning team with *"a mandate to develop and implement programmes of work to improve access to specialist resources, and to improve neonatal outcomes and patient experience, working closely with both providers and commissioners."*⁹

London is by far the largest of these networks, with 13,265 babies admitted to NNUs in 2015-16.¹⁰ There are 27 neonatal units (NNUs) in London, including:

- 8 Level 3 neonatal intensive care units (NICUs), some with specialist surgical teams.
- 15 Level 2 local neonatal units (LNUs) plus nearby two units in Essex, which transfer babies requiring NICU care to London. Level 2 units care for babies born at/above 27 weeks of gestation and are able to offer high dependency care.
- 4 Level 1 special care baby units (SCBUs), providing special care for their local population and sometimes, short-term high dependency care.

Transfers between hospitals are supported by a dedicated Neonatal Transfer Service (NTS). The London NTS offers a neonatal palliative care transfer pathway, described in Annex D.

Paediatric palliative care services vary in each local area. In London, there are:

- 6 children's hospice services
- 3 community palliative care nursing teams
- 3 consultant-led specialist paediatric palliative care teams.¹¹

Each service has its own remit and eligibility criteria, and most support families within a limited geographical area, except for the Louis Dundas Centre, Great Ormond Street (the largest specialist palliative care team), which serves all of the London area and beyond.

An interactive map of these services and ODN boundaries (nationwide) is available on the London Neonatal ODN website [here](#).

2. How the audit was conducted and limitations

The audit was conducted during Summer 2019 by an experienced former neonatal matron (not connected with the project, ensuring a degree of independence) who visited 25 of the 27 neonatal units in the London Neonatal ODN and 2 neighbouring units in Essex, which hosted Study Days.

⁹ NHS (December 2019) *Implementing the Recommendations of the Neonatal Critical Care Transformation Review* (p.6)

¹⁰ Neonatal Critical Care Transformation Review – Evidence review (October 2017) (unpublished) para 4.1.2.

¹¹ Details on these services at: <http://www.londonneonatalnetwork.org.uk/neonatal-complex-and-palliative-care/guidance/>

Information on the remaining two London units was provided by senior staff who worked across more than one unit, so could offer detailed knowledge on them.

The audit was conducted on an anonymous basis to encourage impartial answers and is reported on this basis. Most of the interviews involved senior nursing staff, with consultants joining some.

Information on how practice measured up against 16 standards was gathered using a standard questionnaire, developed by the Pan London Lead Nurse, drawing on a range of guidance on neonatal palliative care:

- NHS Toolkit for high quality neonatal services (2009)
- Practical guidance for the management of palliative care on neonatal units (Mancini et al, 2014)
- The Bliss Baby Charter Standards and Family Friendly Accreditation Scheme (2015)
- Together for Short Lives Perinatal Pathway for babies with palliative care needs (2017)
- The National Bereavement Care Pathway (2018).

Detailed notes were made on each visit, which were typed up before being passed to the independent evaluator, who analysed them thematically.

Findings are presented as a snapshot across the London Neonatal ODN and grouped by level of unit, where this emerged as a significant factor. Aspects of good practice are highlighted, as well as areas for development indicated by the audit. Examples are provided verbatim (i.e. as reported in the audit notes, unedited).

While this provides a rich snapshot of palliative care across the London Neonatal ODN in Summer 2019, there are limitations. The information presented here is as it was reported. Knowledge of individual units indicates that occasionally interviewees may not have been aware of policies or resources available in their unit, did not consider them relevant, or neglected to mention them. There are also a few points (beneath the overarching audit standards) where detailed information was not recorded for every unit. This meant that some findings could not be quantified precisely.

3. Audit findings

The table below lists the audit standards. These have been ‘RAG rated’ (colour-coded, using red, amber, and green) to provide an at-a-glance summary of the audit findings, where:

- **Green** indicates that an audit standard was met in over two-thirds of London’s neonatal units
- **Amber** indicates a wide variation in practice, with around half meeting most aspects of the standard
- **Red** indicates that practice fell short of the audit standard in most neonatal units.

RAG rating	Neonatal Palliative Care Provision: Audit tool
1	Named member of staff: Palliative and end of care is coordinated by a named lead professional and involves multi-agency, multi-disciplinary teams.
2	A dedicated private room: Which is comfortable and private, available for parents to have confidential, sensitive, or difficult discussions.

3	Guidelines/Framework: There is a specific local guideline or framework which is evidence based to support staff in delivering high quality care.
4	Dedicated forum/meeting: <ul style="list-style-type: none"> a) A regular formalised discussion which identifies eligibility for babies for palliative care b) If applicable, antenatal referrals or multi-disciplinary team (MDT) with maternity/foetal medicine teams.
5	Identification tool: Units have an established criteria tool for assessing which babies require palliative care including diagnosis and prognosis.
6	Documentation: The baby has a clear palliative care or end of life care plan documented, which has been agreed with the parents including discussions around: <ul style="list-style-type: none"> • Options of where care can be delivered • Wishes about end of life care • Spiritual, religious, faith, cultural or important rituals.
7	Links with community palliative care services <ul style="list-style-type: none"> • Units have robust links with local palliative care services and hospices to support parents' needs and choices • Units have a collaborative pathway in place • Relevant contact details are accessible for all staff.
8	Memory making opportunities are offered <ul style="list-style-type: none"> • Remember My Baby (photography)/ Footprints/Casts • Chaplaincy - Baptism/Naming/Prayer • Sibling support - know where to signpost.
9	Training & Education <ul style="list-style-type: none"> • Staff have the opportunity to access training on palliative care • Staff have experience in supporting palliative care and have received training to enable appropriate care • Staff have received specific training on how to communicate difficult news.
10	Staff support <ul style="list-style-type: none"> • Do staff have access to a dedicated counsellor/psychologist? • Clinical supervision/reflective practice • Pre-brief/Debrief.
11	Psychological & emotional support for families <ul style="list-style-type: none"> • Do parents have access to a dedicated counsellor/psychologist? • Bereavement support coordinated by a named professional is available if needed • Staff signpost families to bereavement support and counselling if their baby has died on the unit • Families are offered psychological/emotional support after receiving sensitive news.
12	A private room available: For families to spend time with their babies as a family at difficult times or at end of life (<i>differs from Standard 2: room for sensitive discussions</i>).
13	Information and resources for families: Readily accessible for families in language they can understand <ul style="list-style-type: none"> • Include information for siblings and grandparents.
14	After death Families are offered time and privacy to be alone with their baby in a dedicated room <ul style="list-style-type: none"> • Are families offered the option of transferring to a local hospice for use of the 'cool bedroom' or to go home with their baby?
15	Organ donation: Is routinely explored for eligible babies

	<ul style="list-style-type: none"> The unit has a guideline/framework. <p>Post Mortem: Is routinely explored for each baby who dies</p> <ul style="list-style-type: none"> The unit has a guideline/framework.
16	<p>Parent feedback: Feedback from parents is regularly sought, collated, and fed into decision-making processes.</p>

Standard 1: Named member of staff

1	<p>Named member of staff: Palliative and end of life care is coordinated by a named lead professional and involves multi-agency, multi-disciplinary teams. (Bliss Baby Charter reference 2.5C) NHS Toolkit (2009) Principle 2 (2.8.5)</p>
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How does practice across London's neonatal units measure up to this standard?

Although almost all of London's neonatal units said that they have a named lead professional for neonatal palliative care, the scope and influence of this role varied considerably – ranging from a full-time role in a Level 3 unit, to no dedicated time in five smaller units (Levels 2 and 1). Typically, this role is filled by a senior nurse with a little dedicated time, most often one day a month.

As a minimum, this involved keeping contacts and information on local palliative care services up-to-date and keeping on top of relevant paperwork. However, it was clear that the role may extend far beyond this, depending on the experience and capacity of the named lead, to include, for example:

- Regular teaching
- Professional advice and support to colleagues
- Being an integral member of the multi-disciplinary team (see Standard 4), contributing to decision-making around the care of complex babies.

The Level 3 units all reported having at least one senior link person and often, several senior staff with a special interest in palliative care.¹² At present only Chelsea and Westminster Hospital (closely involved in this project since its inception) employ a full-time neonatal palliative care nurse (a clinical nurse specialist), in the first role of its kind nationally. Other examples from the Level 3 units included:

- A multi-disciplinary special interest group for complex babies
- Family liaison nurses playing a lead role, working across NICU and PICU (this role currently exists in two London hospitals)
- A counsellor playing a lead role, as well as two neonatal sisters with some dedicated time.

Practice varied widely in the Level 2 units, ranging from no named person (in two) to:

- Two link nurses; one with two days a week, the other one day a month
- An Advanced Neonatal Nurse Practitioner with a special interest in neonatal palliative care
- Family liaison nurses (similar to those described above)
- A special interest group.

¹² The audit did not gather information on consultants' interest in palliative care, this would be an interesting variable to explore in future.

Although none of the Level 1 units had dedicated time for this role, three had a nurse with a special interest in palliative care, and the other had a senior nurse who kept information up to date. One also drew on the support of the lead professional in a Level 3 unit in a sister hospital.

Aspects of good practice indicated by the audit

- Dedicated time for role
- Dedicated time for teaching
- Special interest group or multi-disciplinary team on palliative care, with lead nurse involvement
- Regular meetings with bereavement midwife, member of bereavement MDT
- Sharing advice and resources with less well-resourced sister hospitals.

Standard 2: A dedicated private room

2	A dedicated private room: Which is comfortable and private, available for parents to have confidential, sensitive, or difficult discussions.
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How does practice across London's neonatal units measure up to this standard?

Thoughtful approaches were evident in units at all levels, although limitations on space made it difficult for some to reserve a dedicated room for difficult conversations with families.

The Level 3 units all had access to suitable rooms (sometimes several), generally well decorated and comfortably furnished, although one included a 'hot desk'.

Around half of the Level 2 units had a dedicated room, while the other Level 2s and all the Level 1 units made use of rooms which doubled as offices, parents' rooms, or expressing rooms. Some had used charitable funds to decorate these rooms sensitively and comfortably.

Aspects of good practice indicated by the audit

- Private and quiet, situated away from the nurseries, able to leave without having to walk through the unit
- Enough room for everyone who may need to be involved: parents, other children potentially, consultant, nurse, chaplain, social worker, psychiatrist etc.
- Free from distractions like phones ringing, papers left on desk, or other people present
- Comfortable furnishings, toys for siblings.

Example (Level 2 unit): *"Excellent room for discussions, can also be used for caring for the baby after death. Near entrance of unit and away from the nurseries, quite private. Comfortable chairs and decorations donated by charity, warm and welcoming."*

Standard 3: Guidelines/framework

3	Guidelines/framework: There is a specific local guideline or framework which is evidence based to support staff in delivering high quality care.
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How does practice across London's neonatal units measure up to this standard?

All but one of the Level 3 units said they had a specific guideline, guidance, framework, or standard operating procedure (SOP) for neonatal palliative care.

Most of the Level 1 and level 2 units were using a guideline (sometimes more than one), referring to a range of resources, listed below. Five said they did not have a guideline, but sometimes used guidance from other units or hospice services involved in a baby's care.

Published guidance/guidelines specifically mentioned included:¹³

- *Practical guidance for the management of palliative care on neonatal units*¹⁴ developed by the Pan London Lead Nurse with colleagues at Chelsea and Westminster Hospital NHS Foundation Trust, in collaboration with the RCPCH (9 mentions)
- Guideline from the Louis Dundas Centre, Great Ormond Street (2 mentions)
- Together for Short Lives pathway: *A Perinatal Pathway for Babies with Palliative Care Needs*, 2017 (2 mentions), also referred to as the 'ACT pathway', an earlier version
- The *National Bereavement Care Pathway* (1 mention) which has a narrower focus
- 'BAPM palliative care framework' (1 mention)
- RCPCH framework (1 mention)¹⁵.

Aspects of good practice indicated by the unit

- Comprehensive pathways, incorporating maternity, neonatal care and bereavement
- Shared approaches with others involved in a baby's care (e.g. community palliative care team, children's hospice service)
- Shared approaches across sister hospitals.

Example: The standard operating procedure (SOP) developed by a Level 3 unit and used in its sister hospital (Level 2 unit) was described as: "*Excellent for whole of maternity and neonates. Clear pathways antenatally, in NICU and post death.*"

Standard 4: Dedicated forum/meeting

4	Dedicated forum/meeting: <ul style="list-style-type: none">a) A regular formalised discussion which identifies eligibility for babies for palliative careb) If applicable, antenatal referrals or multi-disciplinary team (MDT) with maternity/foetal medicine teams.
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How does practice across London's neonatal units measure up to this standard?

All the Level 3 units, most of the Level 2 units, and one Level 1 unit reported that they had regular multi-disciplinary meetings to discuss complex babies, including those eligible for palliative care. This

¹³ Most available at <http://www.londonneonatalnetwork.org.uk/neonatal-complex-and-palliative-care/guidance/>

¹⁴ Mancini A., Uthaya A., Beardsley C., Wood D. & Modi N. (Feb 2014) *Practical guidance for the management of palliative care on neonatal units*, RCPCH and Chelsea & Westminster Hospital NHS Foundation Trust

¹⁵ Probably: Larcher V., Craig F. et al (2015) *Making decisions to limit treatment in life-limiting and life-threatening conditions in children: a framework for practice*

is an encouraging finding, indicating the potential for early consideration of palliative care approaches. A variety of multi-disciplinary forums were used, including:

- Grand rounds (where clinicians meet to reflect on particular cases)
- Psycho-social meetings (to consider families' needs holistically, typically involving a psychologist, social worker, clinicians and sometimes health visitors and community nurses)
- Consultants' weekly meetings
- 'Bed-flow' meetings (to consider which babies are ready to leave the unit)
- Antenatal multi-disciplinary team meetings.

Those that answered 'no' to this question tended to say that such decisions were made on ward rounds; however, half of these reported that a multi-disciplinary team was involved in decision-making antenatally. In all, more than two-thirds of the units mentioned antenatal meetings which might consider babies eligible for palliative care, some involving neonatal consultants.

Aspects of good practice indicated by the unit

- Lead nurse (or other professional) for palliative care attends MDT/forum to consider complex babies
- Nurses confident to recommend consideration of palliative care pathway
- Regular involvement of children's hospice service, specialist, or community palliative care team (mentioned in 5 units)
- Consideration of family's whole needs, involving psychologist, social worker and any others involved e.g. health visitor, community team
- Strong links and information-sharing between maternity and neonatal unit, developing advance care plans (or similar) with parents
- Assigning a named consultant for parents (mentioned by 2 units).

Example (Level 2 unit): Regular meetings with consultant, nurse in charge and registrar to discuss high risk babies or if parental or nursing concerns. Weekly psycho-social meeting (multi-disciplinary) where potential babies are identified. All complicated babies have a named consultant. Plans made for antenatally-diagnosed babies, meeting with parents, neonatal consultants, link nurse if available. Specialist palliative care team attend meetings.

Standard 5: Identification tool

5

Identification tool: Units have an established criteria tool for assessing which babies require palliative care including diagnosis and prognosis.

(Bliss Baby Charter reference 2.5A)

How does practice across London's neonatal units measure up to this standard?

No unit reported having a tool with clear criteria for assessing which babies are eligible for palliative care. However, the existence of such criteria was implied in some other answers to the audit; for example, one unit reported that their Standard Operating Procedure "*makes it clear which babies are eligible antenatally and postnatally*". We do not know if any of the multi-disciplinary forums described under Standard 4 (above) refer to specific criteria, or if decision-making is more fluid, based on clinicians' views of when palliative care may be appropriate. Further research would be

required to provide a more authoritative picture and to explore the potential for supporting improvements in practice against this standard.

Standard 6: Documentation

6	<p>Documentation: The baby has a clear palliative care or end of life care plan documented, which has been agreed with the parents including discussions around:</p> <ul style="list-style-type: none">• Options of where care can be delivered• Wishes about end of life care• Spiritual, religious, faith, cultural or important rituals. <p>(Bliss Baby Charter reference 2.5 D&G)</p>
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How does practice across London's neonatal units measure up to this standard?

Four Level 3 units have their own bespoke neonatal palliative care plan, variously called an 'advance care plan', a 'comfort care plan' or a 'symptom management plan'. Several were using 'Great Ormond Street plans/paperwork' (referred to hereafter as GOS/LDC¹⁶). Two said they had no specific plans beyond those used by the hospice and palliative care teams, if involved.

Among the Level 2 units, just under half reported that they were using palliative care plans, including the GOS/LDC plan, and one was currently developing its own palliative care plan. Nine of the Level 2 units had no specific plan in place, but some referred to plans drawn up by Level 3 units (where babies transfer to/from), plans from the weekly MDT, or the 'normal neonatal plan'. Most of the Level 1 units had no specific plan, although one was using GOS/LDC plans.

More broadly, answers to this question indicate that most units (including those which do not have palliative care plans in place) are routinely offering families options for their baby's care – in hospital, going home, or transferring to a hospice or a combination of those options. Hospice involvement or hospice as an option was mentioned explicitly in two-thirds of responses to this Standard, going home was mentioned in nearly half, and these options were implied in many other responses (e.g. 'all options discussed with parents'). Supporting parents' choices is explored in more detail under Standard 7 (below).

Almost all units reported positively on access to chaplaincy and other religious/spiritual services for families, although detail was lacking.

Aspects of good practice indicated by the unit

- Sharing useful resources – wide use of GOS/LDC plans, some use of hospice plans (3 units)
- Palliative care plans incorporated in the electronic care plans used by nurses (3 units)
- Hospice service involvement (explicit in two-thirds of NNUs), involving hospices 'at an early stage', hospice staff coming to the unit and use of hospice plans.

¹⁶ Probably the GOS 'Emergency Care Plans' or 'Symptom Management Plans' developed by the specialist palliative care team at the Louis Dundas Centre, Great Ormond Street, if they are involved in a baby's care.

Example (Level 2 unit): Very clear care plan and also use 'GOSH'¹⁷ papers if they are involved. All options discussed with parents: unit, hospice or home. Resuscitation, treatment, medication and nutrition plans all documented. All spiritual, religious and faith options discussed.

Example (Level 3 unit): Advance care plans in use. Home offered as option, hospice transfer discussed as option. Psychologist and palliative care nurse involved with supporting parent decisions. Chaplain involved.

Standard 7: Links with community palliative care services

7	<p>Links with community palliative care services</p> <ul style="list-style-type: none">• Units have robust links with local palliative care services and hospices to support parents' needs and choices• Units have a collaborative pathway in place• Relevant contact details are accessible for all staff. <p>(Bliss Baby Charter reference 2.5E)</p>
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How does practice across London's neonatal units measure up to this standard?

There were multiple references to providing nursing support at home from neonatal or paediatric community nurses (and sometimes doctors) to help families to meet a baby's complex healthcare needs after discharge from a neonatal unit.

'Hospice at home' care was mentioned by 11 units, providing nursing and holistic support to families, or supporting some families to return home when their baby is nearing end-of-life or has died. One Level 3 unit reported that they are looking to develop a home extubation pathway, having supported several families to be at home when their baby's life-sustaining treatment was withdrawn.

For the most part, good links with children's hospice services were reported by the neonatal units, mentioned explicitly by three-quarters in their responses to this standard, most commonly supporting families to return home with a baby with complex healthcare needs. There were also examples of units wanting to involve their local hospice 'at an early stage' and encouraging families to visit, as well as hospices providing music therapy and sibling play schemes in unit.

Specialist palliative care teams were mentioned by just under one-third; most often the Louis Dundas, Great Ormond Street palliative care team (9 mentions) which supports families across the London region. Each of London's three palliative care nursing teams were mentioned once.

It was not clear from the audit how far clearly-defined pathways are used in planning and supporting transfers from the neonatal unit to home or hospice service, these were only mentioned by 3 units; there were more references to multi-disciplinary discharge planning meetings, involving staff from the neonatal unit, community nursing, and the hospice if involved.

In the pilot education programme¹⁸ that preceded this project, every neonatal unit was provided with a folder of information on local community palliative care and other support services for

¹⁷ As above. GOSH (Great Ormond Street Hospital) was the term generally used and reported in the audit.

¹⁸ Described in the main report at the start of Chapter 2.

families. Almost all the units visited reported that they had relevant information and contact details readily available to staff on the neonatal unit, with the exception of:

- Two where contact details were said to be held by the consultants or the bereavement midwife
- Two where there was no information file and staff felt that they lacked up to date information and contact details.

Aspects of good practice indicated by the unit

- Early involvement of hospice services to enable trusted relationships to be developed with families
- Multi-disciplinary discharge planning meetings and clear procedures to support transition from hospital to home or hospice
- Involving hospices to support parents and siblings – examples included sibling play schemes, music therapy groups.

Example (Level 2 unit): Neonatal community team involved if home or hospice staff visit. Part of the discharge planning meeting. Unit regularly seeks help from hospice. Access to info for all staff.

Areas for development

Seven units made no mention of working with a children’s hospice service, under this standard.

Standard 8: Memory-making opportunities are offered

8	Memory making opportunities are offered <ul style="list-style-type: none">• Remember My Baby (photography)/ Footprints/Casts• Chaplaincy - Baptism/Naming/Prayer• Sibling support - know where to signpost.
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How does practice across London’s neonatal units measure up to this standard?

Responses to this standard indicate that neonatal units across the London Neonatal ODN have developed thoughtful approaches to memory-making for families who are bereaved, often supported by specialist charities. All appear to offer a good range of memory-making opportunities, with nearly all units mentioning:

- Memory boxes (4Louis, Sands)
- Photographs (most often through *Remember My Baby* volunteers)
- Hand and footprints and/or casts.

Less commonly, neonatal units offered teddy bears and dolls to comfort bereaved parents and siblings (Aching Arms teddies, Lexi dolls); ‘Heart in your hand’ key rings; jewellery-making; fingerprints; illustrations.

Most units said they had good access to multi-faith chaplaincy services, including for blessings and baptism, although detail on this point was not always recorded.

By contrast, support for siblings was patchy. As a minimum, most units provided information for siblings (and sometimes grandparents and extended family) to help them to understand what was happening. Most often mentioned were the leaflets from the bereavement charity, Sands, and two units said that they had special books for siblings.

Five units offered supervised play opportunities for siblings:

- Three of the larger Level 3 units - with a crèche offered twice a week by a local hospice; play on the ward with a Bliss volunteer; or access to paediatric play specialists
- Two of the Level 1 units - where siblings were able to benefit from supervised time in the playroom of the paediatric ward, or access a community playscheme.

More commonly (in 13 units), they looked to local hospice services for sibling support, although around half said that this was only available if a referral had been made.

Aspects of good practice indicated by the unit

One unit said that all staff have been trained in memory-making; anecdotal evidence suggests this may be true more widely.

Areas for development

Six units (one-fifth) acknowledged a gap in information and support for siblings unless a local hospice service was supporting the family.

Standard 9: Training and education

9	Training & Education <ul style="list-style-type: none">• Staff have the opportunity to access training on palliative care• Staff have experience in supporting palliative care and have received training to enable appropriate care• Staff have received specific training on how to communicate difficult news. <p>(Bliss Baby Charter reference 2.4B, 2.5F)</p>
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How does practice across London's neonatal units measure up to this standard?

While varied, most responses indicate that palliative care is becoming embedded in education and training on the great majority of neonatal units in London, although around one quarter (seven units) had little specifically on palliative care, as distinct from bereavement training.

The Study Days provided through this project were mentioned specifically by 22 of the 27 units visited. One unit had not hosted a Study Day.¹⁹

Many units have embedded **palliative care in their regular staff training and education:**

- Training "all staff" in four of the Level 3 units

¹⁹ They declined to engage in this phase of the project.

- As part of regular training in around one-third of units, with time allocated on team away days, study days, focus day, as part of mandatory training (three units) and with protected hours with the education team
- Training for new starters (three units)
- Bitesize modules, e-learning, and ‘snapshot’ teaching in three units.

Hospice study days, staff visits to hospices and training provided by hospice staff were mentioned by 13 units; in addition, staff from two units had joined study days with BLISS and the Rainbow Trust, charities supporting families whose children have life-threatening conditions. Two Level 2 units are developing nurse rotation posts in partnership with local hospices.²⁰

Bereavement training was not the focus of this question but was nonetheless mentioned in many answers, including:

- Annual conference or study day (7 units)
- Training or study days with Sands (4 units)
- Maternity/midwife-led (2 units)
- As part of mandatory training (1 unit).

Just over half the units also reported access to training on difficult conversations/communicating bad news, although often this was only available to doctors. Five felt that this was a gap.

Aspects of good practice indicated by the unit

- Making palliative care part of mandatory training for all staff
- Training new starters
- Nurse rotation posts (pilot in 2 units)
- Ensuring nurses (as well as doctors) access training on difficult conversations with families
- Hospice visits and study days
- Parent participation in study days.

Example (Level 2 unit): Study days as part of this programme. Training by the link nurse (for neonatal palliative care) on yearly mandatory training sessions for all nurses. Yearly study day at local hospice run by the link nurse and the bereavement midwife.

Areas for development

- Seven units have little, if any, training on palliative care (as distinct from bereavement), beyond the Study Days delivered through this project
- Five units felt that difficult conversations/ communicating bad news was a training gap, especially for nurses²¹.

²⁰ <https://chal.org.uk/burdette/>

²¹ Also reflected in feedback on Study Days, see section on training priorities at the end of Annex B.

Standard 10: Staff support

10	Staff support <ul style="list-style-type: none">• Do staff have access to a dedicated counsellor/psychologist? ²²• Clinical supervision/reflective practice• Pre-brief/Debrief.
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How does practice across London's neonatal units measure up to this standard?

Level 3 units were most likely to have a psychologist/psychotherapist/counsellor on unit (some part-time), although one reported "no psychological support for staff except via occupational health".

Across the London Neonatal ODN, six neonatal units said that they do not have regular access for staff to a psychologist, while 12 said they did. Unfortunately, the audit did not yield clear or consistent information on this point for every unit.

Hot²³ debriefs and planned debriefs are widely used if a baby has died, reported in over two-thirds of the units. Planned debriefs appear to be more widely used, with some commenting that hot debriefs could be 'difficult'.

The picture on reflective practice and clinical supervision is unclear, perhaps due to some confusion over the meaning of these terms. With that proviso:

- Eight units reported having reflective practice, including a Level 2 unit which holds 'Schwartz-type' MDT meetings for paediatric and neonatal staff. Another Level 2 unit also reported holding Schwartz Rounds.²⁴
- One unit said that clinical supervision is in place, another was introducing it, and five units said they do not currently have clinical supervision. We lack information on this point from the other units (it may have been conflated with reflective practice).

A variety of other staff group support sessions were mentioned, including monthly doctors' meetings, staff support groups, wellbeing meetings, and meditation sessions.

Aspects of good practice indicated by the unit

- Access to a psychologist or counsellor, individually if required, and through staff group sessions
- Reflective practice embedded, with Schwartz Rounds in some units
- Widespread use of hot and planned debriefs.

Example (Level 2 unit): Psychologist (shared with paediatrics, set NNU days) does reflective practice. Supports parents and staff. Hot debriefs when possible on day and planned debriefs in same week. Monthly meditation sessions for staff and parents. Staff have free access to counselling sessions.

²² Explored in the audit interviews under standard 11 (with psychological support for families), but for the purposes of analysis and reporting, it fitted better under standard 10.

²³ Rapid debriefs carried out as soon as possible.

²⁴ These provide a structured forum for staff to discuss collectively the emotional and social aspects of their work.
<https://www.pointofcarefoundation.org.uk/our-work/schwartz-rounds/about-schwartz-rounds/>

Example (Level 3 unit): Have hot debriefs as required and planned debriefs by consultant and/or psychotherapist. Psychotherapist works three days a week, supports families and staff, offers 1:1s. Monthly doctors' group to support junior doctors. Support group for staff.

Areas for development

There was no, or very limited, access to psychological support for staff in around one-fifth of neonatal units in London. Unfortunately, the audit did not yield clear, consistent information on this standard. This is worthy of further research, given the recognised 'potential for stress, moral distress and burnout' among neonatal nurses and other professionals involved in neonatal palliative care.²⁵

Standard 11: Psychological and emotional support for families

11	<p>Psychological & emotional support for families</p> <ul style="list-style-type: none"> • Do parents have access to a dedicated counsellor/psychologist? • Bereavement support coordinated by a named professional is available if needed • Staff signpost families to bereavement support and counselling if their baby has died on the unit • Families are offered psychological/emotional support after receiving sensitive news. <p>(Bliss Baby Charter reference 2.4 D,E,F,H) NHS toolkit, 2009 (Principle 3: 3.12) Implementing the recommendations of the neonatal critical care review/action 6</p>
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How does practice across London's neonatal units measure up to this standard?

All but one of the Level 3 units have a psychologist (or equivalent role, for example, a counsellor or psychotherapist) to support parents, regularly on the unit, or readily available by referral. The other unit has a part-time psychologist based in the community, with midwives initially offering support to parents who lose a baby in NICU.

Other professionals who work closely with families while their baby is in NICU, such as the lead nurse for palliative care and family liaison nurses (in two hospitals) also play an important role in providing emotional support to families.

Access to psychological support for families who have a baby in NICU varied widely among the Level 2 and Level 1 units:

- 11 units have some time from a psychologist (or equivalent) to support individual families, usually part-time and by referral. Some were working resourcefully, drawing on the support of volunteers and trainees, or sharing a psychologist or counsellor with maternity services, although eligibility was often limited to families whose baby was delivered there. One unit reported that the counsellor would only see mothers, not fathers.
- Many NNUs (all levels) offer supportive group sessions for parents, including coffee mornings, massage, meditation, and meetings attended by the psychologist.

²⁵ Black R. and Honeyman A. (2020) *Support for Staff: Building Resilience in Nurses*, Chapter 3 in Mancini A. et al (2020) *Neonatal Palliative Care for Nurses*, Springer Nature Switzerland.

For bereaved families, some clearer entitlements exist but with much variation between units:

- 10 units said that they offer support from a mental health professional (a psychologist, counsellor or psychotherapist). One Level 3 unit has a bereavement counsellor who supports families for up to a year, while a Level 2 unit said that support from the psychologist could continue for as long as families need it. In another unit, the psychologist was based in maternity and supported bereaved families only if their baby was born there.
- 9 NNUs drew on the support of the bereavement midwife for parents who lose a baby on the neonatal unit, although eligibility was often limited e.g. to babies referred antenatally or to recent births.
- 6 units mentioned support from local hospice services, Sands, or local charities which support bereaved families. One referred families to PETALS²⁶ counsellors, and another 2 were looking to develop this service.
- 5 units said that they organise services of remembrance for bereaved families. In one, the receptionist stays in touch with families and offers practical support, e.g. to visit the mortuary, register the death, and for funeral arrangements.

Example: Contrasting access to psychological support for families in two Level 2 units

Hospital 1	Hospital 2
Psychologist 3 days a week on unit, goes around unit, sees any parent that wants to meet her, also staff identify and refer parents. Sees parents after the death at home and in hospital. Monthly meeting in Mothercare opposite hospital for any parents who have or have had a baby on the unit, with psychologist and staff from neonatal community team.	No counsellor or psychologist. If soon after death, midwives see parents, but no other support. Consultants and staff see parents but not contacted after death.

Nearly one quarter of NNUs reported no psychological support available for families on the palliative care pathway even after bereavement, unless they were eligible for support from the bereavement midwife (typically, if the baby was born there) or by referral to a hospice service, community palliative care services, or a perinatal mental health team which had a waiting list.

Aspects of good practice indicated by the unit

- Easy access to emotional support on the neonatal unit, from the lead nurse for palliative care, social worker, family liaison nurse (where such a role exists), or other suitably experienced professional
- Rapid access to support from a mental health professional for families who need it
- Regular supportive group sessions for families who want this, with input from a mental health professional.

²⁶ Pregnancy expectations trauma and loss society <https://petalscharity.org/about/>

Areas for development

This audit indicates that nearly one quarter of London's neonatal units are unable to offer psychological support to families of babies with life-threatening conditions, even after bereavement, except by referral to other services.

Further research would be required to provide a more authoritative picture. A survey by BLISS in 2018 also highlighted this as an important area for development, finding that 41 per cent of neonatal units in England said that parents had no access to a trained mental health worker; and 30 per cent of neonatal units said parents had no psychological support at all.²⁷

Standard 12: A private room is available

12

A private room available: For families to spend time with their babies as a family at difficult times or at end of life (*different to room for sensitive discussions, Standard 2*).

(Bliss Baby Charter reference 2.4A)

How does practice across London's neonatal units measure up to this standard?

There were examples of thoughtful approaches in all levels of neonatal unit, including:

- Comfortable chairs, and in five units, beds for parents
- Located away from the noise and bustle of intensive care, away from nurseries and the sound of crying babies
- Gases available for babies who have been receiving life-sustaining treatment
- If clinical care is required, nurses/doctors come to room.

A variety of rooms were used, most commonly 'side rooms with gases', also an isolation room and a resuscitation room. Positive examples included comfortable 'rooming-in' rooms²⁸ in six hospitals (mostly Level 2 units) and a dedicated room in maternity, which could be used if a baby was not expected to live more than a few hours after birth; further detail is provided in Standard 14 (below).

A less positive example (in a Level 2 unit) was a room in intensive care, which had no blinds to give the family privacy.

Example (Level 1 unit): Two rooms on the unit may be used for withdrawing life-sustaining treatment. Maternity have a butterfly room where known palliative care cases can give birth and spend time afterwards. Room has hospital bed and normal bed for partner or mum. Neonatal nurses and doctors go to room to give any care midwives are not able to support.

Example (Level 2 unit): Large bedroom with gases available for withdrawing life-sustaining treatment and for care after dying. Room has double bed and is very comfortable for the family.

²⁷ <https://www.bliss.org.uk/news/bliss-releases-new-research-on-mental-health>

²⁸ Rooming-in rooms provide a supported environment for families to stay on the ward with their baby while they develop the skills to meet their baby's healthcare needs e.g. nasogastric tube-feeding, supplementary oxygen, dealing with seizures.

Standard 13: Information and resources for families

13	<p>Information and resources for families: Readily accessible for families in language they can understand</p> <ul style="list-style-type: none">• Include information for siblings and grandparents. <p>NHS Toolkit (2009) Principle 3 (3.12)</p>
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How does practice across London's neonatal units measure up to this standard?

As one might expect in a multi-ethnic community like London, almost every unit²⁹ said they use interpreters where necessary, although one unit (located outside London) reported that it was difficult to find face-to-face interpreters. Some drew on the help of hospital staff who speak community languages, language lines and in one hospital, an online translation service. One hospital mentioned having bilingual health advocates to support patients.

Three of the Level 3 units had developed their own advice and guidance for families, including a booklet for siblings written by a psychologist and a guide to help parents talk about what is happening with their other children, and a leaflet on 'when children die'. Similar resources have been developed in other hospitals.

Around half the units said they made available Sands leaflets for siblings, and (less commonly) for grandparents and other relatives³⁰. Also mentioned were books from CBUK³¹ to help parents discuss the loss of a baby with children, a BLISS³² leaflet on critical care decisions and literature for families from Shooting Star Chase (children's hospice).

Lastly, two units said that they provide information and support on funeral arrangements; this may be more widespread but was not explored specifically in the audit.

Areas for improvement

Where room for improvement was noted, either written information for families was not available or it was narrowly focused on antenatal diagnosis and/or bereavement advice, so felt to be less relevant to families with a baby in neonatal intensive care.

Standard 14: After death, a dedicated room for families to be alone with their baby

14	<p>After death families are offered time and privacy to be alone with their baby in a dedicated room</p> <ul style="list-style-type: none">• Are families offered the option of transferring to a local hospice for use of the 'cool bedroom' or to go home with their baby?
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²⁹ A few units did not provide information on this point.

³⁰ Sands aims to support anyone affected by the death of a baby. <https://www.sands.org.uk/support/bereavement-support>

³¹ Child Bereavement UK <https://www.childbereavementuk.org/resources-when-a-baby-or-child-dies>

³² BLISS is a charity for babies born premature or sick <https://www.bliss.org.uk/parents/support>

How does practice across London’s neonatal units measure up to this standard?

Nearly all the units could offer families a suitable space to spend time with their baby after death, most commonly (in 14 units) using 'rooming-in' rooms³³, which tend to be equipped with comfy chairs, beds and sometimes, kitchens, and bathrooms.

Eight had dedicated room(s), often located in maternity, where families can deliver babies who are not expected to live more than a few hours and spend time together.

Almost all had access to a cool cot (also referred to as a ‘cuddle cot’ or ‘cool blanket’³⁴) allowing families to take their time when saying goodbye to their baby. This was often shared with maternity, and in one unit, could be used at home if the family wished. Only one unit said they did not have access to a cool cot (information was lacking from another two units).

Answers to this question also indicate that families are offered options for end of life care in the great majority of neonatal units in London. Two-thirds of the units (nearly all Level 3s and Level 2s) mentioned transfers to hospice (11) and home (2) or offering both these options (6). Examples of transfers to home or hospice were not provided by Level 1 units.

Aspects of good practice indicated by the unit

- Families are able to spend several hours together with their deceased baby, in a quiet, private, comfortable room
- Families have the option of transferring to a children’s hospice service or going home with their baby after death.

Level 3 unit: One of the rooming-in rooms is a specialist room for bereaved parents, not identifiable by non-staff. Settee can be made into a bed, en-suite. Cool cot available in room. Clear guidance on offering hospice and home after death.

Level 2 unit: Room between maternity and neonatal unit available. If antenatally diagnosed, can deliver in room. En-suite bathroom, area with sofas and somewhere to make drinks and snacks. Cool blankets available for use in the room and also if the baby goes home. Hospice transfers have happened too.

Areas for development

Two units said that transfers to hospice services were only possible if a referral had been made before death, likely reflecting individual hospice referral criteria, funding arrangements, care models or strategy.

Standard 15: Organ donation and post mortem

15

Organ donation: Is routinely explored for eligible babies

- The unit has a guideline/framework.

Post Mortem: Is routinely explored for each baby who dies

- The unit has a guideline/framework.

³³ See previous footnote.

³⁴ Different names were used, probably referring to the same product, the CuddleCot produced by Flexmort.

Organ donation

The audit suggests that great variation persists across London's neonatal units with regards to organ donation, with guidelines in place in only a small minority of units. However, this is a rapidly-developing area and the information collected through the audit may not represent the full picture.

Among the Level 3 units, most said that organ donation had been discussed with some parents, a minority reported that organ donations had taken place. Only two Level 3 units reported having a guideline in place and routinely discuss the possibility of organ donation with parents (example 1, below). Staff in two of the Level 3 units stated that organ donation is discussed only if parents ask about it.

Two of the Level 3 units and one Level 2 unit mentioned recent teaching on organ donation.

Among Level 2s, only two units had a clear policy on organ donation. In one, this was included in the care plan and discussed with parents. In the other, all babies on the palliative care pathway are discussed with the specialist nurse for organ donation (example 2, below).

Across the other Level 2 and Level 1 units, organ donation is not routinely discussed and is not covered by a guideline or framework. Where it had been discussed, this was following an antenatal diagnosis (3 mentions) or because a consultant (5 mentions) or parent (2 mentions) brought it up. A small number of examples were given of procedures carried out, but it was clear that this remains an emerging area of practice.

Example 1 (Level 3 unit): It is "routine" to think about possibility of organ donation, which is included in their comprehensive guideline. Morbidity and mortality³⁵ meetings look at missed opportunities. Staff notify the SNOD (specialist nurse for organ donation) when there is a baby who they think may meet the criteria - close working relationship.

Example 2 (Level 2 unit): All palliative care babies have to be discussed with SNOD team, who will contact parents if donation may be possible – blood types and suitable recipients are thought of first, before speaking to parents.

Post-mortem

The audit indicated more consistent practice in relation to post-mortems, which over two-thirds³⁶ of the neonatal units said they routinely discuss with parents. Twelve units said they have a guideline, framework or checklist which includes this. Five units reported that post-mortems are offered in more limited circumstances, e.g. where an unexpected death has occurred. One unit mentioned recent teaching for their neonatal consultants on this. Five units had information leaflets (including a Sands leaflet) for parents to explain post-mortems.

Aspects of good practice indicated by the audit

- Inclusion of organ donation and post-mortem in unit guidelines

³⁵ Mortality and morbidity meetings are a clinical governance requirement within each NHS Trust, providing an opportunity for multi-disciplinary reflection and learning when a baby has died or things have gone wrong. This process may feed into reporting under the Perinatal Mortality Review Tool (<https://www.npeu.ox.ac.uk/pmrt>) and to MBRRACE-UK (<https://www.npeu.ox.ac.uk/mbrrace-uk/data-collection>) monitoring of perinatal and maternal deaths.

³⁶ We lack information on this point from 2 units.

- Close working with the SNOD (specialist nurse for organ donation)
- Emerging – offer of minimally invasive post-mortems using MRI scans and keyhole surgery.

Areas for development

Great variation in respect of organ donation, much scope for sharing best practice, education, training and resources.

Standard 16: Parent feedback

16	<p>Parent feedback: Feedback from parents is regularly sought, collated and fed into decision-making processes.</p> <p>(Bliss Baby Charter reference 4.1B)</p>
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This emerged as an area for development in almost every neonatal unit in London, with only one Level 3 unit reporting well-developed feedback mechanisms.

Many said they gain feedback informally at the 6-8 weeks (after discharge) follow-up meeting, which tends to involve the lead consultant, sometimes a link nurse and less commonly, a psychologist and/or family liaison nurse, where such a role exists. One Level 3 unit is currently developing a questionnaire to take to this meeting, another said they were 'looking at this'.

Three Level 3 units with dedicated lead nurse, family liaison, or bereavement roles said that they seek feedback from families, but it was not clear how formal this process was or whether feedback was regularly reviewed to inform improvements in services.

One Level 2 unit sends the maternity bereavement experience measure³⁷ to bereaved families, with a prepaid envelope funded by their hospital charity.

It was notable that many of the responses to this standard focused on learning from bereaved families, rather than the much larger group of families with a baby with palliative care needs, discharged home, to hospice or to a local hospital, after a long spell on the neonatal unit.³⁸

Aspects of good practice indicated by the audit

The best example came from a Level 3 unit, which gathers feedback from families in NICU in several ways (in addition to following-up with bereaved families):

- Written feedback, from the 'Friends and Family' forms
- Discussions at their Parents Support group
- A volunteer comes once or twice a month to gather parent feedback at the bedside
- They have carried out two Parent Experience surveys.

³⁷ Standard questionnaire developed by the London Maternity Clinical Network and Sands with support from NHS England <http://www.londonscn.nhs.uk/wp-content/uploads/2017/06/mat-bereavement-mbem-062017.pdf>

³⁸ For data on the number of babies eligible for palliative care and outcomes, see Annex A (table 2).

Annex D

London Neonatal Transport Service: Palliative Care Transfer Pathway³⁹

The London Neonatal Transport Service (NTS) developed a Palliative Care transfer pathway, following consultation with all neonatal units across London. The aim of the pathway is to enable infants to be transferred for end of life care to a location chosen by their family, such as a local hospital or hospice service. They hope to extend this to the patient's home in the future.

The pathway was launched in December 2017. Between December 2017 and August 2019 there were 17 palliative care referrals made to London NTS, of these 14 were carried out. (The remainder fell within other regions, and though the transfers were not carried out by the service, they assisted with planning.)

Any neonatal unit can make a referral to move an infant for palliative care. Three teams are involved from the point of referral – the referring team, the transfer team, and the accepting team at the preferred place of care. There is a formal guideline that includes a quick reference guide, the referral form, and the transfer documentation. Careful planning is essential to ensure seamless patient care between the hospital and the place of end of life care. The team asks for a lead time of 48 hours in most cases, although more urgent transfers may be considered if all aspects of care are already in place at the point of referral.

On the day of planned transfer, a conference call between all teams takes place before team despatch. This is to confirm the family are still wishing for the transfer to take place, it also serves to confirm the aspects of clinical care that have been agreed and to ensure specialist equipment that an infant might require is available for transfer or already at the place of eventual care. The transfer team consists of medical, nursing and ambulance staff. Parents are given the opportunity to travel with their baby or may choose to travel independently.

Handover takes place on arrival and the care plan, that has already been established, begins. Following all such transfers, the whole team takes part in a debrief. Such cases are challenging, and staff can take up individual support should they wish.

³⁹ With thanks to Dr Faith Barker, Lead Consultant for Palliative Care, for confirming details on this service (15 May 2020).