

# Supporting documents

## **Practical guidance for the management of palliative care on neonatal units**

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## 1. Aim of the systematic review

The aim of the systematic review was to answer the following set of questions.

- How is the infant managed once a decision to withdraw or withhold life-sustaining treatment has been made? Management was considered in the following categories:
  - Pain and symptom control
  - Monitoring of the infant
  - Management of fluids and nutrition
  - Ventilation and oxygen
  - Location of care
- How are conflicts about end of life decisions on the neonatal unit resolved in practice?
- What support should be offered to parents and families once palliative care is instituted for an infant, and what bereavement support should be provided? Support was further classified as:
  - Religious, pastoral or spiritual
  - Psychological and emotional
- What is good practice in relation to seeking consent for post mortems and organ donation in infants and what are the practicalities of this?
- What support do staff need when managing an infant receiving palliative care.

## 2. Stakeholder involvement

### 2.1 The guidance development group

The composition, disciplines and expertise of the Steering Group and the Guidance development group can be found in Appendix 1. There were no competing interests declared.

### 2.2 Views of target population

The guidance has been subject to two rounds of stakeholder consultation. A full list of stakeholders and feedback can be seen in Appendices 2, 6, 7, 8 and 9.

## 3. Methods

### 3.1 Search strategy

The search strategy was designed to identify publications relating to the management of newborn infants in whom a decision to institute palliative care has been made. We conducted a phase one search after generating a set of criteria using the PICOS guidelines using the subdivisions 'population', 'intervention', 'comparator', 'outcome' and 'study design'. A list of search terms was created as defined below.

**Population:** The target population are neonates and infants in whom a decision to institute palliative of care has been made. Articles that dealt with neonatal palliative care in the home environment were included. A decision was made to include papers that discussed and explored neonatal euthanasia and the Groningen protocol.

**Interventions and comparators:** Palliative care is defined as 'the active, total care of patients whose disease is not responsive to curative treatment; the goal of palliative care is achievement of the best possible quality of life for patients and their families'.

**Outcomes comprising:**

- Management to alleviate distress
- The withdrawal and withholding of life sustaining treatment
- Identification of optimal care needs for infants on the neonatal unit at the end of life
- Provision of spiritual fulfilment for families
- Best practices for family support including support through the bereavement process

**3.2 Search construction**

The search was designed to be systematic and repeatable. Searches were carried out using OVIDsp to search electronic databases, Ovid Medline (R) 1948 to July week 2 2011; Embase from 1980 to week 28 July 2011 and PsycINFO 1967- July week 2 2011. Search criteria were drawn up by Dr Sabita Uthaya and Dr Katherine Sharpey and confirmed or amended by the research team. These criteria are shown in Appendix 3.

**Electronic databases searched:**

- Ovid Medline (R): 1948 to week 2 July 2011
- Embase: 1980 to week 28 2011
- PsycINFO: 1967 to week 2 July 2011

**3.3 The search**

The above databases were searched on 2 March 2011; the search was repeated on 21 July 2011 using the criteria listed in Appendix 3. Citations were exported to Reference Manager and duplicates were removed. The full text of selected papers was obtained through the library of Imperial College London and the British Library.

The initial search included all types of study design and results were assessed against the inclusion criteria. Papers identified by the search criteria that conformed to the inclusion criteria were included in the review process outlined below. Each abstract from the phase one search was read separately by three members of the team (Dr Katherine Sharpey, Dr Sanjay Valappil and Dr Sabita Uthaya). Any paper not dealing with palliative care was excluded. Subsequently each abstract was reviewed further based on the following inclusion and exclusion criteria and a decision to include it was made by the guidance development group. Where the abstract was not available or a decision could not be made, the full paper was reviewed prior to a decision on inclusion being made.

Papers were included if they were:

- Related to palliative care
- Addressed end of life care
- Addressed practical considerations once palliative care has been decided upon including decisions made in the antenatal period
- Related to neonates and infants up to and including one year of age where the infant is on a neonatal intensive care unit
- Concerned patients resident in a hospital neonatal unit, hospice, or under a hospice programme at home
- Covered any conditions including congenital anomalies or lethal conditions
- Covered all aspects of medical and surgical care e.g. ventilation/ fluids/ nutrition / antibiotics/ symptom control/ monitoring / location
- Written in the English language
- Dealt with neonatal euthanasia and the 'Groningen protocol' where there were aspects related to palliative care
- Covered practical aspects of bereavement or care of the family including pastoral and spiritual support, follow up care
- Cover staff support in relation to neonatal palliative care
- Concerned the resolution of conflict between parents and staff as well as between members of staff
- Of any study design, including observational, qualitative, case series, commentaries and personal practice were included as it was anticipated that there were unlikely to be many quantitative studies published in this area

Papers were excluded if they were:

- Written in a language other than English
- Published before 1980
- Unable to be obtained
- Dealt exclusively with care provided on paediatric intensive care units or relating to adult palliative care

- Concerning the decision making process alone
- Concerning the ethics of the decision making process
- Concerning educational programmes
- Relating to staff attitudes to palliative care
- Related to the legal aspects of withdrawal and withholding of life sustaining treatment
- Related to the ethical and legal issues around euthanasia
- Commentaries /editorials which did not add to the original paper being commented on

The full papers of any relevant abstracts of onward citations that were not part of the original outcome of the search were read. The guidance development group agreed to include the papers in the results if the papers met the inclusion criteria as set out above.

### 3.4 Categorisation of the information

Selected papers were placed into one or more of five subject categories according to the clinical questions we were seeking to address as listed in the section titled 'Aims of the systematic review'.

## 4. Classification of the evidence

Classification of Evidence Levels	
1++	High quality meta-analyses, systematic reviews of RCTs or RCTs with a very low risk of bias
1+	Well conducted meta-analyses, systematic reviews or RCTs with a low risk of bias
1-	Meta-analyses, systematic reviews or RCTs with a high risk of bias
2++	High quality systematic reviews of case control or cohort studies. High quality case control or cohort studies with very low risk of confounding or bias and a moderate probability that the relationship is causal
2+	Well conducted case control or cohort studies with a low risk of confounding or bias and a moderate probability that the relationship is causal
2-	Case control cohort or cross sectional studies with a high risk of confounding or bias and a significant risk that the relationship is not causal
3	Non-analytic studies e.g. case reports/case series
4	Expert Opinion

### 4.1 Categorisation of quality of individual papers

Once relevant papers were selected and agreed for inclusion by the guidance development group they were further reviewed for quality based on the study design and methodology. The group used Critical Appraisal Skills Programme tools<sup>1</sup>, Agree II tool and NICE guideline development recommendations<sup>2</sup> to support and inform the review process.

There was limited evidence that conformed to traditional study design review processes so the guidance development group agreed to grade the papers according to relevance and utility.

Each paper was critically appraised using the Critical Appraisal Skills Programme tool where such a tool was available for the relevant study design. This applied to papers that were reviews, qualitative research and observational studies. This was carried out by 2 reviewers trained in critical appraisal (Ms Alex Mancini and Dr Sabita Uthaya). It was agreed that where disagreements were encountered these would be resolved by discussion with a third reviewer also trained critical appraisal (Professor Neena Modi). For papers based on consensus the AGREE II instrument was applied.

For expert opinion, commentaries and editorials the main conclusion was extracted and this was summarised in the evidence tables.

<sup>1</sup> <http://www.casp-uk.net/>

<sup>2</sup> The Guidelines Manual. National Institute for Clinical Excellence, 2009

## 4.2 Synthesis of the evidence

For each subject category a series of statements were drawn up summarising the evidence giving weight to those studies that were critically appraised to have greater relevance and utility.

## 4.3 Recommendations

For each subject category a series of recommendations was made. Where the evidence was considered to be moderate or higher this was used as the basis for the recommendations. Where the strength of the evidence was low or absent, recommendations are based on consensus within the guidance development group. It was recognised that the guideline itself would rely heavily on consensus agreement as the chosen topic has not been heavily researched. The recommendations were circulated to stakeholders and guidance users for consultation; comments received were considered for incorporation by the guidance development group in to the final version, and where relevant, recording the reasons for not incorporating comments. A full list of comments received from stakeholders and the response to them in the two rounds of stakeholder consultation is included in Appendices 6 and 8. The response to comments from the RCPCH Clinical Standards Committee is included in Appendices 7 and 9.

For most of the topics within the guidance the quality of the evidence was not good, mainly consisting of small descriptive and cross sectional studies, expert opinion and non- systematic reviews of the literature. Hence, the guidance recommendations have been written as a summary of the alternatives and the clinical experience of the GDG. (Grade E in the table below)

Grades of Recommendation	
A	At least one meta-analysis, systematic review or RCT rated as 1++ and directly applicable to the target population; or A body of evidence consisting principally of studies rated as 1+ directly applicable to the target population, and demonstrating overall consistency of results
B	A body of evidence including studies rated as 2++ directly applicable to the target population and demonstrating overall consistency of results, or extrapolated evidence from studies rated as 1++ or 1+
C	A body of evidence including studies rated as 2+ directly applicable to the target population and demonstrating overall consistency of results or extrapolated evidence from studies rated as 2++
D	A body of evidence level 3 or 4 or extrapolated evidence from studies rated as 2+
E	Recommended best practice based on the clinical experience of the guidance development group

## 5. Results

The initial search yielded 753 papers in Ovid Medline (R), 1392 papers in Embase and 43 papers in PsycINFO. Phase one searching resulted in 1,714 citations after duplicates were excluded in Reference Manager. Of the 1,714 citations 16,60 were excluded in Phase two of systematic review of reading the abstracts.

- 20 papers were excluded because they related to the ethics of decision- making.
- 101 papers were excluded because they related to the process of arriving at a decision to institute palliative care.
- 57 papers were excluded because they related solely to the ethics of palliative care.
- 10 papers were excluded because they related solely to euthanasia.
- 29 papers were excluded because they related to staff attitudes.
- 5 papers were excluded because they related to legal issues that did not have a bearing on management of the infant.
- 31 papers were excluded because they were editorials or commentaries on papers that did not add any more information to that obtained from the original papers.
- 20 papers were excluded because they related to adult palliative care.
- 60 papers were excluded because they related solely to palliative care in paediatric medicine.
- 5 papers were excluded because they related to educational programmes in palliative care.
- 1318 papers were irrelevant.

This resulted in 54 citations for inclusion in the systematic review (fig 1). Two papers were included as an onward citation resulting in a final total of 56. These papers are listed in Appendix 5.

## 6. Implementation and resource implications

In order for these guidelines to be effectively implemented it is important that all healthcare professionals who deal with neonates receiving palliative care receive education and training. This includes doctors in training, nurses, midwives and senior doctors. Some recommendations will require additional resources that may not be available in all neonatal units. This was highlighted in the response from stakeholder consultations. Factors that will aid facilitation include widespread dissemination of the guidance via the stakeholders involved in the development.

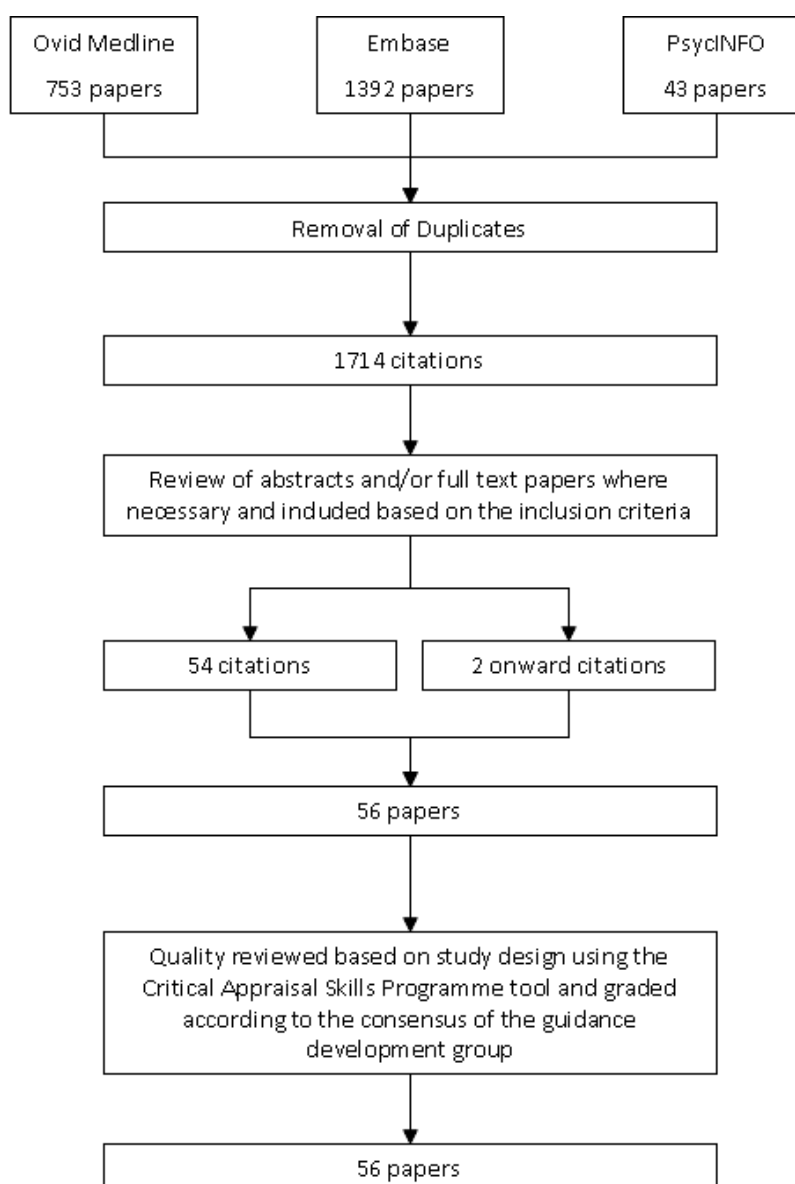
## 7. Audit

Standards for auditing the provision of palliative care in the neonate should be developed.

## 8. Guidance update

The Guidance document will be updated every 5 years. This will include a literature review and stakeholder consultation.

**Figure 1: Flow diagram**



## 9. Evidence tables

### 1. How should the infant be managed once a decision to withdraw or withhold life-sustaining treatment has been made?

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Abe, N Catlin, A	2001	Studying Ventilator Withdrawal	Retrospective chart review in level 3c NICU and level 2a NICU in LA. 1997-98	72 Neonates	<b>Pain and Symptom Control</b> <ul style="list-style-type: none"> <li>12/18 were given pain medication</li> <li>Of the 12: <ul style="list-style-type: none"> <li>3 – Fentanyl drip (discontinued when ventilator support withdrawn)</li> <li>7 – no drip, given bolus as ventilation and IV withdrawn</li> <li>3 – chart showed medication but medication not given</li> </ul> </li> <li>88% - IV lines removed when ventilation was discontinued</li> <li>Range of time of death 5 minutes – 10 days</li> <li>6/18 – no pain medication offered during life or at withdrawal of life support</li> <li>Ventilation/Oxygen</li> <li>66% received Inotropes at time of ventilation removal</li> <li>43% of the 66% had drip discontinued at the same time as the ventilation was removed</li> <li>1% weaned off Dopamine</li> <li>2/18 received Neuromuscular Blocking agents which were withdrawn when ventilation was removed. 1/18 had Nitric Oxide and Prostaglandin – both discontinued when ventilation was stopped</li> </ul>	Limitation of study is that it is retrospective and documentation was described as poor.	3
Bell	2004	Practical guidance on neonatal palliative drug use	Summary of known information			Description of various pharmacological agents and doses	4
Berner, ME Rimensberg, PC	2006	Comparison of aspects of withdrawal of LST and national directives at a Swiss NICU	Prospective set of data over a 3 year period and a questionnaire completed by the attending physician in charge of the case at the time of death	34 Neonates	<ul style="list-style-type: none"> <li>82% opiates</li> <li>18% benzodiazepines</li> <li>59% respiratory support removed</li> <li>35% respiratory and circulatory support removed</li> <li>6% circulatory support removed</li> <li>21% died after withdrawal of life support</li> <li>24% died after withholding life support</li> <li>79% - futility stated as reason</li> <li>21% - poor developmental outcomes stated as a reason</li> <li>No paralysing Neuromuscular Blockers use at the time of foregoing LST</li> </ul>	Prospective study. Applicability limited as based on the Directives of the Central Ethics Committee of the Swiss Academy of Medical Sciences	3
Bhatia, J	2006	Palliative care in the fetus and newborn			<ul style="list-style-type: none"> <li>Importance of comfort care – eg provision of a separate room for the parents to be with the dying infant</li> </ul>	Key recommendations summarised. In agreement with papers of higher category of evidence.	4



Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Calhoun, B Napolitano, P Terry, M Bussey, C Hoeldtke, NJ	2003	Describes experience in providing a programme of structured multi-disciplinary team care for fetuses with lethal abnormalities and the perinatal hospice	Evaluation of patient experience/usage	33 parents	<ul style="list-style-type: none"> <li>85% chose to participate in the program</li> <li>39% IUD</li> <li>61% delivered alive</li> <li>All babies delivered alive died within 20 minutes and 2 months</li> <li>Where babies were born alive, there were no maternal complications</li> </ul> <p><b>Conclusion</b></p> <ul style="list-style-type: none"> <li>The availability of a structured programme provides ongoing comprehensive multi-disciplinary team support</li> <li>A structured programme of postnatal palliative care offers a tangible and safe alternative to early elective pregnancy termination of fetuses with lethal abnormalities</li> </ul>	Retrospective summary of practice at one centre. User acceptability may be applicable to other centres. Follow up complete.	3
Carter, BS	2004	To look at principles in palliative care in respect of location of care			<ul style="list-style-type: none"> <li>Best interests of the patient should be the focus</li> <li>Physical comfort of the infant requires close management</li> </ul>		4
Carter, BS Bhatia, J	2001	To report the multidisciplinary developmental process of a comfort care guideline for the NICU in the setting of palliative care.	Delphi	Medical, nursing, administrative and ancillary professional staff in the NICU and Obstetric department	Clinically practical guidelines can be institutionally derived and locally implemented in relation to palliative care in newborns.	Description of methodology used in producing the guideline published separately.	4
Carter, BS Hubble, C Weise, K	2006	Addresses unique challenges of providing palliative care in the NICU and identifies several current programs			Although barriers exist to implementing palliative care teams within the NICU the concepts remain sound and the models for successful integration of practices in these settings exist	Doesn't discuss methods for overcoming barriers in detail	4
Carter, BS Leuthner, SR	2003	Ethics of withholding/withdrawing nutrition	Discussion		<p><b>Fluids and Nutrition</b></p> <p>Once fluids and nutrition have been withheld/withdrawn:</p> <ul style="list-style-type: none"> <li>Oral nutrition should be provided if infant shows signs of hunger/thirst</li> <li>Nutritional needs should be assessed on a comfort care basis, not for future growth needs</li> <li>Skin and mucous membrane care to prevent symptoms of discomfort from thirst or hunger</li> <li>Pain and Symptom Control</li> <li>Benzodiazepine and morphine</li> </ul>	Key recommendations extracted.	4

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Carter, BS Howenstein, M Gilmer, MJ	2004	Circumstances surrounding the death of hospitalised children	Retrospective medical record review at 1 hospital 1 July 2000-31 June 2001	Neonates/ infants who had received inpatient care at end of life – 33 neonates	<b>Pain and Symptom Control</b> <ul style="list-style-type: none"> <li>30% receiving pain relief at time of withdrawal of life support</li> <li>85% had pain medication ordered</li> </ul> <b>Fluids and Nutrition</b> <ul style="list-style-type: none"> <li>18% died within 48hrs after nutrition withdrawn</li> </ul>	Retrospective and dependent on documentation in medical notes.	3
Catlin, A Carter, B	2002	Development of a neonatal end of life palliative care protocol	Delphi		Presents recommendations for all aspects of palliative care	Consensus developed in the US. Differences in practice for example in management of withdrawal of neuromuscular blockade.	4
Cavaliere, T	2007	Palliative care at home vs NICU pro position	Expert opinion			Personal opinion of location of palliative care – case for providing it at home	4
Cooke, RW	2004	Discusses the views of clinicians in 10 European countries on active euthanasia and legal implications			<ul style="list-style-type: none"> <li>Opinions among health professionals vary widely</li> <li>Even where it is already practised there is no uniform support for legalisation. Active euthanasia accepted and practised – Netherlands, France, Lithuania</li> <li>Nurses more likely to support</li> </ul>	Key conclusion extracted.	4
Craig, F Goldman A	2002	Home management of the dying NICU patient			<ul style="list-style-type: none"> <li>Suggests a model of care for palliative care in the home including symptom control and pain relief – detailed guidance is provided</li> </ul>	Evidence to support home management is based on paediatric study.	4
Cuttini, M Nadai, M Kaminski, M Hansen, G De Leeuw, R Lenoir, S Persson, J Rebagliato, M Reid, M De Vonderweid, U Lenard, HG Orzalesi, M Saracci, R	2000	Survey on how physicians in different countries confront the ethical issue of foregoing LST in newborn infants to reach end of life decisions	Anonymous self administered questionnaire	122 NICUs in Luxembourg, Netherlands, Sweden, France, Germany, UK, Italy and Spain	<ul style="list-style-type: none"> <li>89% response rate</li> <li>61-96% reported having been involved at least once in setting limits to intensive care due to incurable conditions</li> <li>46-90% reported having been involved at least once in setting limits to intensive care because of baby's poor neurological prognosis</li> <li>28-90% reported withdrawal of mechanical ventilation</li> <li>Widespread use of continuation of treatment without intensification and withholding of emergency manoeuvres</li> <li>France – 73% reported administration of drugs with the aim of ending life</li> <li>Netherlands – 47% reported administration of drugs with the aim of ending life</li> <li>Highlights wide variations between countries</li> </ul>	Question accuracy of results – raises the question of underreporting due to illegal practices	2-

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Gale, G Brooks, A	2005	Importance of palliative care policy, pathway and guidelines			Description of the implementation of a NICU based team approach to providing end of life care to dying infants and families	Description of personal practice	4
Hawdon, JM Williams, S Weindling, AM	1994	Case studies looking at home extubation	3 case studies – practice over a 6 month period	3 case studies	<ul style="list-style-type: none"> <li>Offering choice of location of care including the home in a systematic way allows parents to be empowered</li> <li>multi-disciplinary team approach is essential</li> </ul>	Subjective – no clarification of why particular case studies were chosen	3
Hazebroek, FW Smeets, RM Bos, AP Ouwens, C Tibboel, D Molenaar, JC	1996	Staff attitudes towards continuation of life-support in newborns with major congenital anomalies	Questionnaires	46 patients	<ul style="list-style-type: none"> <li>Attitudes towards the continuation of LST unanimous in 39/46 patients</li> <li>In remaining 7 cases staff would have preferred a different support mode that the one given</li> <li>Attitudes were influenced by the patient's risk of mortality</li> <li>Decision about life support of newborns with life threatening problems should include all disciplines involved in patient care and should be made at an early stage</li> </ul>	Small sample size with risk of bias	3
Hoeldtke, NJ Calhoun, BC	2001	Model of care for prenatal diagnosis.				No additional information than that contained in paper by same authors summarised previously.	4
Howe, TH	2007	Palliative care at home vs NICU con position	Expert opinion			Personal view	4
Laing, IA Piyasena, C	2008	Commentary on AAE Verhagen – Analgesics, sedatives and neuromuscular blockers as part of end of life decisions in Dutch NICUs, 2009				UK practice reiterated.	4
Larcher, V Hird, MF	2002	Discusses practice of withholding and withdrawing LST on a neonatal unit			<ul style="list-style-type: none"> <li>Summary of the decision making process and practical aspects of withdrawing and withholding LST</li> <li>Practical management to address sedation and paralysis and location of care</li> </ul>	In agreement with papers of higher category of evidence.	4

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Leuthner, SR Pierucci, R	2001	Evaluation of palliative care consultation service	NICU in Wisconsin Measuring referral rates and barriers to referral Retrospective chart review - diagnosis, timing of referral to palliative care team in relation to infant clinical course, reasons for referral, recommendations made, outcomes and whether recommendation were followed	12 babies who received palliative care consultations on NICU over 13 months	<ul style="list-style-type: none"> <li>12/51 babies who died had neonatal palliative care consultations</li> <li>39 (76%) infant deaths occurred without palliative care consultations – suggests availability is not the main barrier as all babies on the unit have access to palliative care teams</li> </ul>	Retrospective chart review. Small sample size.	3
Leuthner, SR	2004	Describes experience in providing a programme of structured multi-disciplinary team care for fetuses with lethal abnormalities and the perinatal hospice			<ul style="list-style-type: none"> <li>Provides guidance for managing infants with lethal abnormalities</li> </ul>	Recommendations based on expert experiences	4
Leuthner, SR Boldt, AM Kirby, RS	2004	Examination of place of death and hospice/home health care options in Wisconsin	Collected information from death certificates where cause of death was congenital abnormality or a condition of the perinatal period	2591 infants died between 1992 - 1996. 1538 (60%) were caused by congenital abnormality or condition of the perinatal period	<ul style="list-style-type: none"> <li>Of 508 congenital abnormalities 9% deaths occurred at home</li> <li>Of 1030 conditions of the perinatal period 1.5% deaths occurred at home</li> <li>40% of 91 hospices/home support agencies that responded provided services to the paediatric population</li> <li>Concluded that there is a low home death rate in infants in comparison to adults and older children</li> </ul>	Limited as no data on numbers of cases offered a home death or whether hospice availability effect parents' decisions	3
Leuthner, SR	2004	Review which addresses multi-disciplinary team approach in planning the care of an infant who will die from lethal abnormality or prematurity			<ul style="list-style-type: none"> <li>Includes detailed care plans for fetal and newborn palliative care</li> </ul>	Personal practice in line with papers with higher level of evidence	4

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Lundqvist, A Nilstun, N	2003	Review of end of life practices in Sweden	Questionnaire sent to the head nurse of each unit – qualitative and quantitative with space for additional comments  Questions created using recommendations from Catlin and Carter papers.  <b>4 sections:</b> <ul style="list-style-type: none"> <li>• practice before birth</li> <li>• practice after birth,</li> <li>• practice when the baby was dying,</li> <li>• practice after the death</li> </ul>	Overview of practice in 38 neonatal units in Sweden	<ul style="list-style-type: none"> <li>• Response rate 32/38</li> <li>• Of those units just under 200 neonates died</li> <li>• 41% units – parents offered opportunity to choose time to remove ventilator</li> <li>• 32% units – permit neonate to die at home</li> <li>• 97% units – collect mementos</li> <li>• 97% units – had consent to autopsy when requested</li> <li>• 82% units – had a follow up visit</li> <li>• Practice largely similar in all neonatal units – Practice should be standardised</li> <li>• Guidance should allow for scope of individuality of babies</li> </ul>	Relied on the head nurse of unit providing information on end of life care on that unit. Assumes that response is representative of practice on that unit.	2-
Matthews, AL O'Conner-Von, S	2008	To examine the relationship between neonatal weight and neonatal comfort care	Retrospective chart review of neonates who died after withdrawing or withholding LST in a level 3 NICU in America	171 neonates	<ul style="list-style-type: none"> <li>• 27.5% - no comfort medication</li> <li>• Neonates that weigh less than 800gms are less likely to receive comfort medication</li> <li>• Recommends consideration of comfort care in smaller neonates</li> </ul>	Small sample study – recommends that it is repeated with a larger cohort	3
McHaffie, H Fowlie, P	1998	Discussion of Royal College of Paediatrics and Child Health (RCPCH) framework for withdrawing and withholding	Used results of in-depth interviews used in previous studies as part of discussion	57 doctors 119 nurses across 6 neonatal units in Scotland	<ul style="list-style-type: none"> <li>• Concludes that the framework does address concerns of clinicians</li> <li>• Provides reassurance and a good source of reference</li> <li>• Should enable neonatal teams to reflect on their practice</li> <li>• Highlights that the framework does not address withholding of feeds</li> <li>• Indicates that district general hospital consultants are more likely to speak with university based centres if seeking further discussion of a case</li> </ul>	Comment on RCPCH guidance	4

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Moratti, S	2011	Discusses the use of neuromuscular blockers in connection with abstention decisions in neonatology and the boundaries between deliberate ending of life and other end of life decisions	Used a hypothetical case study and asked neonatologists whether it would be acceptable to administer neuromuscular blockers and whether such behaviour should be reported	14 Dutch neonatologists	<ul style="list-style-type: none"> <li>• Showed that the use of neuromuscular blockers in certain situations are currently a subject of discussion among Dutch neonatologists</li> <li>• Many respondents reported feeling threatened by the potential involvement of the criminal law authorities</li> </ul>		4
Moro, T Kavanaugh, K Okuno-Jones, S Vankleef, JA	2006	Synthesis of empirical research on neonatal end of life care in North America over ten years	<b>Restricted search:</b> <ul style="list-style-type: none"> <li>• Neonates only</li> <li>• Only research, not clinical guidance or ethics</li> <li>• Excluded research on decision making</li> <li>• Excluded research in Europe due to legal euthanasia</li> </ul>		<b>10 articles split into 4 categories</b> <ul style="list-style-type: none"> <li>• Withdrawing or withholding of LST</li> <li>• Pain management at ventilator withdrawal</li> <li>• Parents and the decision making process</li> <li>• Dying process</li> </ul> <p>7/10 papers focus on decision making before withdrawing LST.</p> <p>7/10 not focussed on palliative care – just end of life</p>	Not systematic review, more of a summary of the evidence. Excluded Dutch papers because of papers on euthanasia.	3
Munson, D	2007	Providing a practical approach to the withdrawal of LST, specifically mechanical ventilation	Case Study as an example and provides some general principles for staff		Provides guidance for all aspects of palliative care	Personal practice in line with recommendations of papers with higher category of evidence.	4
Nelson, RM Shapiro, RS	1995	Looks at the role of the institutional ethics committee in resolving conflict between parents and staff on the NICU			<ul style="list-style-type: none"> <li>• The primary role of the committee is to be used as a forum for open discussion</li> <li>• Consensus may be the result but should not be the goal</li> <li>• The committee should be admissible in judicial proceedings but its advisory position should not</li> </ul>		4
Partridge, JC Wall, SN	1997	Determine frequency of opiate analgesia administration to infants when life support is withdrawn or withheld	Retrospective case review at a level 3 NICU in California	All deaths (165) in a 3 year period – looked at 121 deaths that were attributable to withdrawing or withholding of life support	<ul style="list-style-type: none"> <li>• 84% received opioid analgesia as life support was withheld or withdrawn</li> <li>• 64% of infants who received opiates were given doses in the usual range</li> <li>• Birth weight was not different for infants who were given opiates and those who were not</li> <li>• Infants with NEC, major anomalies or chromosomal disorders were more likely to be given opiates than infants with other diagnoses.</li> </ul>	Single unit study and retrospective	3

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Pierucci, RL Kirby, RS Leuthner, SR	2001	Discussion experience and effects of a palliative care consultation service for neonates and infants	Retrospective chart review at a children's hospital in Wisconsin	196 of those who died <1 year of age during a 4 year period (1 January 1994-31 December 1997)	<ul style="list-style-type: none"> <li>13% had palliative care consultations</li> <li>Rate increased from 5% in 1994 to 38% in 1997</li> <li>Infants of families who received palliative care consultations had fewer days in intensive care, fewer interventions and invasive procedures and the families had more frequent referrals for chaplains and social services</li> <li>Suggests that palliative care consultations may enhance end of life care</li> </ul>	Single unit study and relies on documentation as retrospective.	3
Porta, N Frader, J	2007	Discussion of ethics of withholding hydration and nutrition in newborns			<ul style="list-style-type: none"> <li>Decisions to stop any form of life support should focus on the clinical circumstances not the means to sustain life</li> </ul>	Moral arguments presented for decision making but no evidence to support	4
Romesberg, TL	2007	Addresses comfort care and end of life decision making, and bereavement support and highlights challenges	Review		<ul style="list-style-type: none"> <li>Further work should be undertaken to evaluate emotional, ethical and financial challenges in palliative care</li> </ul>	Personal practice in line with other papers with higher level of evidence	4
Stenekes, s, Harlos, M, Lambert, D Hohl, C, Chochinov H, Ens, C	2011	Describe indications and clinical situations for use of intranasal fentanyl and practicalities of use	Retrospective chart review of neonates and infants receiving intranasal fentanyl in palliative care	40 charts reviewed. 7 infants under paediatric palliative care service received intranasal fentanyl	<ul style="list-style-type: none"> <li>Results not provided in abstract</li> </ul>	Description of practice	4
Stringer, M Shaw, VD Savani, RC	2004	To supply evidence based comfort care guidelines for neonates			<ul style="list-style-type: none"> <li>Recommends guideline development for end of life care – based on comfort care.</li> </ul> <p><b>4 key areas:</b></p> <ul style="list-style-type: none"> <li>Provision of warmth</li> <li>Close physical contact</li> <li>Nutritional support</li> <li>Sedation and pain management</li> </ul>	Consensus restricted to single unit. Practice in line with other papers with higher level of evidence	4
Van der Heide, A Van der Maas, PJ Van der Waal, G Kollee, LA Leeuw, R	2000	To describe the frequency, background and impact of decisions to give analgesic or other drugs that may, intentionally or unintentionally, shorten the life-span of severely ill neonates.	Retrospective cross sectional study of physicians in the Netherlands - questionnaires	338 consecutive infant deaths under 1 year of age August – November 1995	<ul style="list-style-type: none"> <li>Potentially life shortening drugs (mostly opioids) administered in 37%</li> <li>Most physicians caring for infants who are going to die feel the medication is appropriate for use even if it shortens life</li> <li>Distinguishing between intentionally ending life and providing adequate terminal care by alleviating pain or other symptoms is not easily made</li> </ul>	Retrospective questionnaire.	2-

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Verhagen, AA Dorscheidt, JH Engels, B Hubben, JH Sauer, PJ	2009	To describe type, doses and reasons for administering medications as part of end-of-life decisions in the Dutch NICU's	Retrospective notes review	340 newborn deaths with a preceding end of life decision over 12 months	<ul style="list-style-type: none"> <li>224/340 were given analgesics or sedatives before the end of life decision was made</li> <li>292/340 were given analgesics or sedatives after the end of life decision had been made</li> <li>Medication increased in 94/289 infants in whom death was imminent</li> <li>Medication increased in 110/150 who had a poor prognosis</li> </ul> <p><b>Reasons for the increase in medication:</b></p> <ul style="list-style-type: none"> <li>4% hastening death</li> <li>55% no reason documented</li> <li>16% received neuromuscular blockers because they had either already received or to stop or prevent gasping</li> </ul>		3
Williamson, A Devereux, C Shirtcliffe, J	2009	Development of care pathway for babies being discharged from a level 3 unit into the community for end of life care	Collaborative project between level 3 NICU, local children's hospice and local PCT		<ul style="list-style-type: none"> <li>Enables parents to decide where they want their baby cared for</li> <li>Enables rapid referral</li> </ul>	Lack of detail of care pathway and methodology of development.	4
Wright, V Prasun, MA Hilgenberg, C	2011	Study to identify factors that make the delivery of end of life care sporadic	Questionnaire – to examine attitudes toward a number of key barriers	50 NICU nurses working in a level 3 NICU	<ul style="list-style-type: none"> <li>98% respondents were women</li> <li>86% reported having providing palliative care</li> <li>98% agreed palliative care is as important as curative care</li> <li>100% pain relief is a priority</li> <li>64% stated that staff are asked by parents to extend life beyond what the nurse thought was right</li> <li>78% reported that end of life guidance existed in their unit</li> <li>46% had received training</li> </ul>	Single centre. Restricted to nurses.	3

## 2. How are conflicts about end of life decisions on the neonatal unit resolved in practice?

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Berner, ME Rimensberg, PC	2006	Comparison of aspects of withdrawal of Life Sustaining Treatment (LST) and national directives at a Swiss NICU	Prospective set of data over a 3 year period	34 Neonates	<ul style="list-style-type: none"> <li>There were no cases where withholding and withdrawing of LST was undertaken without parental agreement</li> <li>Ethics committees were never involved</li> </ul>	Prospective but no details provided on how conflicts if any were resolved.	3
Larcher, V Hird, MF	2002	Discusses practice of withholding and withdrawing LST on a neonatal unit			<ul style="list-style-type: none"> <li>Disagreements should be resolved by negotiation, conciliation and compromise</li> <li>Emphasis importance of follow up</li> </ul>	Summary of expert opinion	4



Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Nelson, RM Shapiro, RS	1995	Looks at the role of the institutional ethics committee in resolving conflict between parents and staff on the NICU			<ul style="list-style-type: none"> <li>The primary role of the committee is to be used as a forum for open discussion</li> <li>Consensus may be the result but should not be the goal</li> <li>The committee should be admissible in judicial proceedings but its advisory position should not</li> </ul>	Summary of expert opinion	4
Verhagen, AA De Vos, M Dorscheidt, JH Engels, B Hubben, JH Sauer, PJ	2009	To examine the frequency and background of conflicts	Review of medical files in 10 Dutch NICUs and semi-structured interviews with neonatologists about the decision making process	359 newborns of which 150 had preceding end of life decisions	<ul style="list-style-type: none"> <li>Conflict between team members occurred in 6/147 (4%) due to a disagreement in prognosis</li> <li>Conflict between team and parents occurred in 18/147 (12%)</li> <li>Resolved by postponing end of life decision until consensus was achieved</li> </ul>	Data collected relied on documentation in the medical notes. Describes steps used to arrive at consensus with parents.	3

### 3. What support should be offered to parents and families once palliative care instituted for an infant and what bereavement support should be offered to these families?

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Abe, N Catlin, A	2001	Studying Ventilator Withdrawal	Retrospective chart review in level 3c NICU and level 2a NICU in Los Angeles 1997-98	72 Neonates	<ul style="list-style-type: none"> <li>83% of parents received support – documented <ul style="list-style-type: none"> <li>83% - from each other and social work</li> <li>33% - clergy</li> <li>28% - other family members</li> <li>11% - friends</li> </ul> </li> <li>60% of parents were provided with keepsakes</li> <li>22% were referred for additional support</li> <li>No documentation of referral to support groups</li> </ul>	Limitation of study is that it is retrospective and documentation was described as poor.	3
Armentrout, D	2009	Parents' perspective following removal of infant life support	Qualitative study of parents' perspective when making the decision to remove life support		<ul style="list-style-type: none"> <li>Parents realised that there is no real 'choice'</li> <li>No real decision to be made so anger less likely</li> <li>Parents did the 'best they could under the circumstances</li> <li>Regrets – not providing as much parental support at time of withdrawal of ventilation and not sharing the infant with other family members for memories</li> </ul>	Qualitative study	3
Bhatia, J	2006	Palliative care in the fetus and newborn	Expert summary		<ul style="list-style-type: none"> <li>Importance of comfort care – eg provision of a separate room for the parents to be with the dying infant</li> </ul>	Key recommendations summarised. In agreement with papers of higher category of evidence.	4

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Calhoun, B Napolitano, P Terry, M Bussey, C Hoeldtke, NJ	2003	Describes experience in providing a programme of structured multi-disciplinary team care for fetuses with lethal abnormalities and the perinatal hospice	Evaluation of patient experience/usage	33 parents	<ul style="list-style-type: none"> <li>• Creating memories</li> <li>• Providing chaplaincy, social services and nurse support</li> <li>• Providing parents with unlimited time with their infant</li> </ul>	Retrospective summary of practice at one centre. User acceptability may be applicable to other centres. Follow up complete.	3
Calhoun, BC Hoeldtke, NJ Hinson, RM Judge, KM	1997	Perinatal Hospices				Editorial summary	4
Carter, BS	2004	To look at principles in palliative care in respect of location of care			<ul style="list-style-type: none"> <li>• Contributions from community paediatricians who have relationships with families can be helpful</li> <li>• Care should be consistent with the goals and preferences of the family and respectful of culture and traditions</li> </ul>	Summary of expert opinion	4
Carter, BS Bhatia, J	2001	Local comfort care guidelines	Delphi		<ul style="list-style-type: none"> <li>• Family encouraged to visit and access support e.g. Chaplain/social worker</li> </ul>	Description of methodology used in producing the guideline published separately.	4
Catlin, A Carter, B	2002	Development of a neonatal end of life palliative care protocol	Delphi		<ul style="list-style-type: none"> <li>• Presented recommendations of planning and education, family care, recommendations when death does not occur, family follow up</li> </ul>	Consensus developed in the US. Differences in practice for example in management of withdrawal of neuromuscular blockade.	4
Craig, F Goldman A	2002	Home management of the dying NICU patient			<ul style="list-style-type: none"> <li>• Suggests a model of care for palliative care in the home including symptom control and pain relief – detailed guidance is provided</li> </ul>	Evidence to support home management is based on paediatric study.	4
Gale, G Brooks, A	2005	Importance of palliative care policy, pathway and guidelines			<ul style="list-style-type: none"> <li>• Description of the implementation of a NICU based team approach to providing end of life care to dying infants and families</li> </ul>	Description of personal practice	4
Haas, F	1987	Review of bereavement care with a focus on seeing the body in adults, children and neonates			<ul style="list-style-type: none"> <li>• Suggestion that holding a dead baby distracts from the grieving process and may affect bonding with subsequent babies</li> <li>• Must respect the view of parents</li> <li>• Suggests photos can be taken for parents to view at a later date</li> </ul>	Summary of expert opinion	4

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Harvey, S Snowdon, C Elbourne, D	2008	Review of effectiveness of interventions to support families and facilitate emotional adjustment following the death of a baby	Systematic review of literature. Part of the BRACELET study		<ul style="list-style-type: none"> <li>Concluded that empirical base of current practice is limited and more research is needed</li> </ul>	Very few quantitative studies available on subject, so no statistical analysis conducted. Searches yielded 1588 citations, 109 selected and reviewed, of these very few concentrated exclusively on NICU parents	2++
Kain, VJ	2006	Looks at barriers faced by neonatal nurses providing palliative care	Developed survey		<ul style="list-style-type: none"> <li>Recommends that staff are trained in palliative care management to provide support to families</li> </ul>	Literature specifically related to neonatal nursing was limited – looked at critical care, intensive care and palliative care nursing	3
Larcher, V Hird, MF	2002	Discusses practice of withholding and withdrawing life support treatment on a neonatal unit			<ul style="list-style-type: none"> <li>Highlights importance of clinical guidelines and good communication between staff and parents</li> <li>Parents should be provided with information and be closely involved in the dying process</li> <li>Creating memories and spending time with the child is important for care of the family</li> <li>Follow up should be made by someone from the unit who is known to the parents within 2 months of death</li> <li>Annual memorial services are good practice</li> </ul>	In agreement with papers of higher category of evidence.	4
Leuthner, SR Pierucci, R	2001	Evaluation of palliative care consultation service	NICU in Wisconsin Measuring referral rates and barriers to referral Retrospective chart review – diagnosis, timing of referral to palliative care team in relation to infant clinical course, reasons for referral, recommendations made, outcomes and whether recommendation were followed	Babies who received palliative care consultations on NICU over 13 months	<ul style="list-style-type: none"> <li>12/51 babies who died had neonatal palliative care consultations</li> <li>39 (76%) infant deaths occurred without palliative care consultations – suggests availability is not the main barrier as all babies on the unit have access to palliative care teams</li> </ul>	Retrospective chart review. Small sample size.	3

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Leuthner, SR	2004	Describes experience in providing a programme of structured multi-disciplinary team care for fetuses with lethal abnormalities and the perinatal hospice			<ul style="list-style-type: none"> <li>Provides guidance for managing infants with lethal abnormalities including support of the family</li> </ul>	Recommendations based on expert experiences	4
Lundqvist, A Nilstun, N	2003	Review of end of life practices in Sweden	<p>Questionnaire sent to the head nurse of each unit – qualitative and quantitative with space for additional comments</p> <p>Questions created using recommendations from Catlin and Carter papers.</p> <p><b>4 sections:</b></p> <ul style="list-style-type: none"> <li>practice before birth</li> <li>practice after birth,</li> <li>practice when the baby was dying,</li> <li>practice after the death</li> </ul>	Overview of practice in 38 neonatal units in Sweden	<ul style="list-style-type: none"> <li>Response rate 32/38</li> <li>Of those units just under 200 neonates died</li> <li>41% units – parents offered opportunity to choose time to remove ventilator</li> <li>32% units – permit neonate to die at home</li> <li>97% units – collect mementos</li> <li>97% units – had consent to autopsy when requested</li> <li>82% units – had a follow up visit</li> <li>Practice largely similar in all neonatal units – Practice should be standardised</li> <li>Guidance should allow for scope of individuality of babies</li> </ul>	Relied on the head nurse of unit providing information on end of life care on that unit. Assumes that response is representative of practice on that unit.	3
McHaffie, H Lyon, AJ	2001	Explore parents' perspectives of lingering death	Semi-structured face to face interviews after baby's' death	59 sets of parents of 62 babies 3 and 13 months after death	<ul style="list-style-type: none"> <li>22% found the length of time it took for their baby to die distressing. Deaths that clinicians expected to be swift had a 3-36 hour range</li> <li>Where babies lingered doubts remained</li> <li>Where there was a swift death the decision to withdraw/withhold life support was confirmed</li> <li>Parents need to be fully prepared for what might happen once life support is withdrawn</li> </ul>	Small sample size with risk of bias	2-

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
McHaffie, HE Laing, IA Lloyd, DJ	2001	Follow up care of bereaved parents after treatment withdrawal from newborns	Face to face interviews	62 babies born over 2 calendar years in the East of Scotland	<ul style="list-style-type: none"> <li>22% seen by 6 weeks after the death</li> <li>10% not recalled before 6-11 months</li> <li>8% not seen at all in the first year</li> <li>All except one couple saw the neonatologist who had cared for their baby</li> <li>33% recalled a nurse being present</li> <li>88% seen in the study hospital</li> </ul> <p><b>Recommendations from parents:</b></p> <ul style="list-style-type: none"> <li>Appointments should be scheduled within 2 months of the death whether autopsy results are available or not</li> <li>Should see the named neonatologist</li> <li>Should be in a setting away from the hospital where possible</li> </ul> <p><b>Parents value:</b></p> <ul style="list-style-type: none"> <li>Efforts to find out how they are coping</li> <li>Full and frank information given sensitively</li> <li>Reassurance where possible</li> </ul>	Small sample size with risk of bias	3
Moore, DB Catlin, A	2003	Discussion of lactation suppression			<ul style="list-style-type: none"> <li>Emphasises the importance of the care of the mother</li> </ul>	Summary of expert opinion	4
Moro, T Kavanaugh, K Okuno-Jones, S Vankleef, JA	2006	Synthesis of empirical research on neonatal end of life care in North America over ten years	<b>Restricted search:</b> <ul style="list-style-type: none"> <li>Neonates only</li> <li>Only research, not clinical guidance or ethics</li> <li>Excluded research on decision making</li> <li>Excluded research in Europe due to legal euthanasia</li> </ul>		<p><b>10 articles split into 4 categories</b></p> <ul style="list-style-type: none"> <li>Withdrawing or withholding of LST</li> <li>Pain management at ventilator withdrawal</li> <li>Parents and the decision making process</li> <li>Dying process</li> <li>7/10 papers focus on decision making before withdrawing LST.</li> <li>7/10 not focussed on palliative care – just end of life</li> </ul>	Not systematic review, more of a summary of the evidence. Excluded Dutch papers because of papers on euthanasia.	3
Munson, D	2007	Providing a practical approach to the withdrawal of LST, specifically mechanical ventilation	Case Study as an example and provides some general principles for staff		<ul style="list-style-type: none"> <li>Guidelines should be developed and used locally.</li> <li>Describes principles of palliative care including support of families</li> </ul>	Personal practice in line with recommendations of papers with higher category of evidence.	4
Pierucci, RL Kirby, RS Leuthner, SR	2001	Discussion experience and effects of a palliative care consultation service for neonates and infants	Retrospective chart review at a children's hospital in Wisconsin	196 of those who died <1 year of age during a 4 year period (1 January 1994-31 December 1997)	<ul style="list-style-type: none"> <li>13% had palliative care consultations</li> <li>Rate increased from 5% in 1994 to 38% in 1997</li> <li>Infants of families who received palliative care consultations had fewer days in intensive care, fewer interventions and invasive procedures and the families had more frequent referrals for chaplains and social services</li> <li>Suggests that palliative care consultations may enhance end of life care</li> </ul>	Single unit study and relies on documentation as retrospective	3

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Romesberg, TL	2007	Addresses comfort care and end of life decision making, and bereavement support and highlights challenges	Review		<ul style="list-style-type: none"> <li>Further work should be undertaken to evaluate emotional, ethical and financial challenges in palliative care</li> </ul>	Personal practice in line with other papers with higher level of evidence	4
Williams, C Munson, D Zupancic, J Kirpalani, H	2008	Provide a practical and consistent approach, tailored to individual families, to bereavement support in North America			<b>Approach includes:</b> <ul style="list-style-type: none"> <li>Clear and consistent communication compassionately delivered</li> <li>Shared decision making</li> <li>Physical and emotional support</li> <li>Follow up medical, psychological and social care</li> </ul>	Summary of expert opinion, providing practical perspective and referring to literature with a high category of evidence	4
Williamson, A Devereux, C Shirtliffe, J	2009	Development of care pathway for babies being discharged from a level 3 unit into the community for end of life care	Collaborative project between level 3 NICU, local children's hospice and local Primary Care Trust		<ul style="list-style-type: none"> <li>Enables parents to decide where they want their baby cared for</li> <li>Enables rapid referral</li> </ul>	Lack of detail of care pathway and methodology of development.	4

#### 4. What is good practice in relation to seeking consent for post-mortems and organ donation in infants and what are the practicalities of this?

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Catlin, A Carter, B	2002	Development of a neonatal end of life palliative care protocol	Delphi		<ul style="list-style-type: none"> <li>Presents recommendations for all aspects of palliative care including practical guidance on post mortem and organ donation</li> </ul>	Consensus developed in the US. Differences in practice for example in management of withdrawal of neuromuscular blockers.	4
Leuthner, SR	2004	Review which addresses multi-disciplinary team approach in planning the care of an infant who will die from lethal abnormality or prematurity			<ul style="list-style-type: none"> <li>Includes detailed care plans for fetal and newborn palliative care including post mortem and organ donation</li> </ul>	Recommendations based on expert experiences	4

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
McHaffie, H Fowlie, PW Hume, R Laing, IA	2001	Determine parents' views on autopsy after treatment withdrawal	Semi-structured face to face interviews after baby's death	59 sets of bereaved parents (108 individual parents) – all but 1 were asked for PM	<ul style="list-style-type: none"> <li>62% agreed to autopsy</li> <li>Reasons for declining autopsy: <ul style="list-style-type: none"> <li>Fear of disfigurement</li> <li>Leave child in peace</li> <li>No unanswered questions</li> </ul> </li> <li>Consent to autopsy influenced by: <ul style="list-style-type: none"> <li>Diagnosis</li> <li>Age of child</li> <li>Approach and attitude of clinician</li> </ul> </li> </ul>	Small sample size with risk of bias	3

### 5. What support do staff on the NICU need when managing an infant receiving palliative care?

Author(s)	Year	Aim of Paper	Methods Used	Sample if relevant	Results/Recommendations	Comments based on Critical Appraisal	Classification of Evidence Level
Catlin, A Carter, B	2002	Development of a neonatal end of life palliative care protocol	Delphi		<ul style="list-style-type: none"> <li>Highlights important of debriefing staff</li> <li>Staff counselling</li> <li>Moral support for staff</li> </ul>	Consensus developed in the US. Differences in practice for example in management of withdrawal of neuromuscular blockers.	4
Gale, G Brooks, A	2005	Importance of palliative care policy, pathway and guidelines			<ul style="list-style-type: none"> <li>Description of the implementation of a NICU based team approach to providing end of life care to dying infants and families including staff support</li> </ul>	Description of personal practice	4
McHaffie, H Fowlie, P	1998	Discussion of Royal College of Paediatrics and Child Health (RCPCH) framework for withdrawing and withholding	Used results of in-depth interviews used in previous studies as part of discussion	57 doctors 119 nurses across 6 neonatal units in Scotland	<ul style="list-style-type: none"> <li>Concludes that the framework does address concerns of clinicians</li> <li>Indicates that district general hospital consultants are more likely to speak with university based centres if seeking further discussion of a case</li> </ul>	Comment on RCPCH guidance	4
Yam, BM Rossiter, JC Cheung, KY	2001	Study to examine the experiences of NICU nurses in Hong Kong	Interviews	10 NICU nurses	<b>8 themes emerged</b> <ul style="list-style-type: none"> <li>Disbelieving</li> <li>Ambivalence and helplessness</li> <li>Protecting the emotional self</li> <li>Providing optimal physical care to the infant</li> <li>Providing emotional support to the family</li> <li>Expressing empathy</li> <li>Lack of knowledge and counselling skills</li> <li>Conflicting values in care</li> </ul>	Small sample exploratory study, relevant to Hong Kong practice. Interviews undertaken in Cantonese and translated and transcribed by third author – question of accuracy	2-

# Appendix 1

## Development Groups

### Project Steering Group

#### Membership

Name	Designation
Professor Neena Modi	Professor of Neonatal Medicine, C&WFT
Alex Mancini	Neonatal Matron, C&WFT
Dr Sabita Uthaya	Consultant Neonatologist, C&WFT
Ria Lane	Project Manager, C&WFT
Rita Ranmal	Clinical Standards Co-ordinator, RCPCH

### Guidance Development Group

#### Membership

Name	Designation
Alex Mancini	Neonatal Matron, C&WFT
Christina Beardsley	Head of Multi-Faith Chaplaincy
Daniel Wood	Clinical Psychologist
Dr Sabita Uthaya	Consultant Neonatologist, C&WFT
Professor Neena Modi	Professor of Neonatal Medicine, C&WFT
Ria Lane	Project Manager, C&WFT
Rita Ranmal	Clinical Standards Co-ordinator, RCPCH



# Appendix 2

## Stakeholders

Available upon request from the authors.

# Appendix 3

## Search Criteria

Searches	Results
1	neonat\$.mp
2	infant\$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
3	bab\$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
4	newborn\$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
5	gestat\$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
6	infant/ or infant, newborn/ or infant, low birth weight/ or infant, small for gestational age/ or infant, very low birth weight/ or infant, extremely low birth weight/ or infant, postmature/ or infant, premature/
7	1 or 2 or 3 or 4 or 5 or 6
8	terminal care/ or euthanasia/ or euthanasia, active/ or euthanasia, passive/ or hospice care/ or resuscitation orders/ or suicide, assisted/
9	palliative care/
10	withholding treatment/ or euthanasia, passive/
11	(comfort adj3 care).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
12	(end adj of adj life adj care).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
13	Terminally ill/
14	(terminal\$ adj care\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
15	(withhold\$ adj3 treatment\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
16	(terminal\$ adj3 ill\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
17	(palliat\$ adj3 care\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
18	palliat\$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
19	(lethal\$ adj abnorm\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
20	(congen\$ adj abnorm\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
21	8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18 or 19 or 20
22	exp Intensive Care, Neonatal/
23	(neonat\$ adj intensive\$ adj care\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
24	Intensive Care Units, Neonatal/
25	(intensive\$ adj care\$ adj unit\$ adj neonat\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
26	Delivery Rooms/
27	(deliver\$ adj room\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
28	(deliver\$ adj suit\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
29	(labour\$ adj ward\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]

Searches	Results
30	(special\$ adj care\$ adj bab\$ adj unit\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
31	Nurseries, Hospital/ or Nurseries/
32	nurser\$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
33	Hospices/
34	hospice\$.mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
35	Birthing Centers/
36	(birth\$ adj cent\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
37	(birth\$ adj unit\$).mp. [mp=protocol supplementary concept, rare disease supplementary concept, title, original title, abstract, name of substance word, subject heading word, unique identifier]
38	22 or 23 or 24 or 25 or 26 or 27 or 28 or 29 or 30 or 31 or 32 or 33 or 34 or 35 or 36 or 37
39	7 and 21 and 38
40	Limit 39 to (english language and yr="1980-Current")

# Appendix 4

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## Appendix 5

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# Appendix 6

## Consultation One: Stakeholder Comments

Available upon request from the authors.

# Appendix 7

## Consultation One: RCPCH Comments

Available upon request from the authors.

# Appendix 8

## Consultation Two: Stakeholder Comments

Available upon request from the authors.

## **Appendix 9**

### **Comments from RCPCH Clinical Standards Committee and responses from GDG**

Available upon request from the authors.

# Appendix 10

## Response to RCPCH letter dated 2 September 2013

Available upon request from the authors.