

## Efficient evidence reviews

### Scottish Government Review of Maternity and Neonatal Services

#### Models of Care for infants requiring neonatal services and their parents

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#### Summary and Recommendations

The aim of this rapid review was to distil core principles and practice recommendations that could lead to **effective, equitable, sustainable and acceptable care provision for infants requiring neonatal care and their families**. Establishing a positive parent/baby relationship is crucial for promoting the well-being and development of infants requiring neonatal services. In order to achieve the best outcomes for such infants, the model of care therefore needs to be developed with this in mind. The review identified **30 systematic reviews**, which were broadly divided into the following categories: parents' views and experiences of neonatal care units (n=11); methods for improving family-centred care (n=10); service configuration (n=5), transitional/discharge care (n=3) and workforce configuration (n=1). In addition, **thirteen primary studies** not included in the systematic reviews and which examined service (n=9) and workforce configuration (n=4), were also identified and included in the review. Guidelines from British Association of Perinatal Medicine (BAPM) and the Department of Health, and a NICE quality framework were also identified as part of the review.

The evidence from the systematic reviews of parents views and experiences of neonatal care for their infant were generally judged to be of poor quality due to lack of critical appraisal conducted by the review authors. However, some key themes did recur across the reviews and these could be considered in the designing the optimal model of care for neonatal services which also take the families' needs into account. Specifically, we can stipulate that **families need to have the opportunity to have as much contact with the baby as possible and as far as possible be involved in providing care including breastfeeding and kangaroo care and also decision-making processes**. A family-centred model of care such as this, enables parents to take on a parental identity and provide a sense of normality, at a very stressful time. In order to facilitate this, **staff need to be trained on aspects of family-centred care such as breastfeeding and kangaroo care**. It is also essential that a **positive relationship is built up with the health professionals** looking after the infant, whereby, they are welcoming to parents (i.e. do not act as gatekeepers), provide plenty of opportunity for questions and help empower parents to look after their infant.

In terms of interventions/actions for improving family-centred a range of reviews of diverse interventions were identified. Two of these were **high quality Cochrane reviews on the use of kangaroo care in stable infants, which reported a wide range of benefits** in terms of infant and mother outcomes. A **well-conducted HTA review found strong evidence that short periods of kangaroo care (up to 1hr) increased the duration of breastfeeding up to 1 month post discharge**. There was also evidence that simultaneous pumping with an electric pump has advantages for the duration of breastfeeding in the first two weeks. **Strong evidence was found for peer support**

**delivered at home or in hospital.** BFI accreditation of the maternity unit was also associated with an increase in number of infants receiving any breastmilk – new guidelines for BFI accreditation for neonatal units are now available and may be beneficial – evaluation is needed. In addition Benzies et al. (2013) reported that **parenting programmes** (educational interventions, psychosocial support and developmental interventions) helped to **reduce maternal anxiety and depressive symptoms and had positive effects on self-efficacy and connectivity.** However, there was considerable heterogeneity and there was no specific intervention that consistently conferred the most benefit. In addition, the systematic reviews also identified area where the evidence is lacking. Specifically, one Cochrane review examined cot-nursing versus incubator care on temperature control and weight gain in preterm infants and reported that there was no significant difference in temperature control and weight gain when a heated water filled mattress was used instead of an incubator. However, this was based on a small number of small studies and the authors urge caution in interpreting the results and urging more research in this area. Another Cochrane review on the use of audio recordings of consultations with parents identified no studies, also highlighting a gap in this area.

Five systematic reviews examined configuration of services, specifically, regionalisation of care and neonatal transport. These reviews had a significant number of limitations in terms of included studies (e.g. date of publication, poor quality, lack of studies) so pertinent primary literature was sought instead. The primary studies also focused on the effect of regionalisation of neonatal care in terms of outcomes related to neonatal mortality and morbidity and also place of birth. It should be cautioned that these studies observational and potentially at risk of bias, but they were conducted in either UK or EU settings and may represent the best available evidence. Together, **these studies suggest that regionalization of neonatal services can increase the number of very preterm infants and VLBW infants being delivered in high activity neonatal intensive care units,** and this may result in a decreased mortality rate for the most vulnerable infants. However, whilst centralisation of intensive care services may provide the optimal outcomes for very preterm, VLBW and very sick infants **a different model of service provision would potentially be more appropriate for preterm infants who are more mature (>32 weeks) or higher birth weight (>1500g) and otherwise stable.** Any service configuration that requires babies to move a distance from their home should proactively consider how to support parents to remain in close contact with their infants and also facilitate a return to more localised care as soon as possible to ensure parental involvement can be optimised.

Only one review examining workforce configuration was identified and this reported that low nurse-patient ratio was associated with higher mortality. Whilst this review was of adequate quality, the included studies were of variable quality and caution is needed when interpreting their results. Due to the lack of systematic review level evidence, four additional primary studies were identified and included in the review. Again these studies have limitations, particularly as they are observational. However, they do suggest that **under-staffing and over-crowding are associated with poorer outcomes for infants requiring care.** In addition, one study specifically examined the effect of specialist nursing provision and provided evidence in support of increasing this particular form of provision. Addressing understaffing could potentially improve outcomes, it is recommended that an economic analysis is conducted to explore this further.

Finally only one systematic review, which included one study on early supported discharge was identified. Whilst this showed positive results, it highlights a dearth of evidence in this area and a **need for further research to examine the safety, efficacy, acceptability, and resource implications of early supported discharge.**

A small number of guidelines from the Department of Health, Royal College of Nursing (RCN) and BAPM, BFI and the NICE quality framework were identified. **These also highlight the potential importance of a family centred-approach to neonatal care and provide guidance on how to promote this.** In addition they provide practical details relating to service and workforce configuration.

Finally, these results should be viewed in conjunction with the rapid reviews on improving interprofessional working and also the maternal critical care review, both of which highlighted **the need for joined-up care.** This applies to care the mother and the baby may individually receive from different professionals and/or services, but also to care that affects both the mother and the baby jointly. For instance, in providing support for breastfeeding in the neonatal unit or in the case of mothers who are unwell or have had a difficult birth. Moreover, in the case of multiple births care and attention must be given to ensure that these principles are adhered to so that parents are offered help to be in contact and provide breastmilk with all of their babies who may be receiving different levels of care (e.g. see Multiple Births Foundation, 2011). **The mother and babies (and father) should therefore be considered as one unit and care should be delivered in a manner which recognises this.**

The following recommendations are based upon the evidence presented below. In order to provide guidance on core principles and practice recommendations, the recommendations have been framed in accordance with the Framework for Quality Neonatal and Newborn Care (Renfrew et al., 2014).

**The evidence:**

- Database Search identified a total of 1955 records. After screening 29 systematic reviews met the inclusion criteria. These reviews were broadly divided into the following categories: parents' views and experiences of neonatal care units (n=11); methods for improving family-centred care (n=9); regionalisation of neonatal care (n=5), transitional/discharge care (n=3) and workforce configuration (n=1). An additional seven primary studies on service and workforce configuration were also identified in the search and included within the review.
- NICE (1 quality framework identified, 1 guideline on donor milk banks),
- SIGN (no relevant guidelines identified),
- Cochrane Neonatal Group (5 reviews relevant to review identified, also identified in database search),
- Department of Health (2 guidelines),
- BAPM (5 guidelines),
- RCPH (no additional records found),
- RCM (no additional records found),
- RCN (two guidelines),
- BFI (guide to standards)
- Expert consultation (6 additional primary studies, 1 additional systematic review, 1 additional rapid review)
- Scottish Government Consultation (2 additional records found: 1 primary study and the RAND report on provision of neonatal services) and the English Maternity Services Review (no consideration of provision of neonatal care).

From the evidence (in the form of systematic reviews and primary studies) it is possible to make some high level recommendations that rest upon the data found. It is possible to distil information on core principles on models of neonatal care (in terms of practice categories, values and philosophy of care), and organisation of care, and care providers that may lead to the best outcomes for all infants and their families. It should be noted that there are more detailed and nuanced recommendations provided specifically by some studies/guidance which are detailed within the review.

**Core Principles:**

**Practices**

- All parents of infants requiring neonatal care should be involved as much as possible in the provision of care for their child (e.g. through kangaroo care, breastfeeding) and in the decision making process.
- Staff caring for mothers (ie midwives, obstetricians, physicians, GPs, health visitors) and those caring for babies (ie neonatal nurses, neonatologists, transport services) should communicate effectively about ways of maximising contact between mother and baby/babies, and enabling women to breastfeed/express breastmilk.
- Donor milk banks should be available for all women and babies and operated in accordance with NICE guidelines.

**Values and Philosophy**

- Care for babies in neonatal units and their parents should be baby- and family-focussed and tailored to their individual needs.
- Good, clear, empathic communication with parents should be a priority.
- Continuity of care and good interprofessional working is important in this environment which can be stressful and difficult for parents and staff.
- Neonatal units should be welcoming places for parents both in terms of staff attitudes and environments and should offer all parents a private and comfortable space to spend as much as possible with their baby/babies.
- The most vulnerable babies (e.g. very preterm or very low birthweight) should be cared for in level III units which have high levels of such cases. Parents should be enabled to stay together with their baby when babies are cared for far away from the family home.
- Barriers to contact and breastfeeding should be tackled, such as inappropriate routines in care, and a lack of private space and support.

**Organisation of care:**

- Very preterm and/or very low birthweight and/or very sick babies are wherever possible born in units with level III facilities and high volumes of very preterm and/or very low birth weight babies.
- If very preterm and/or very low birthweight and/or very sick babies are born in a setting without level III facilities and high volumes of very preterm and/or very low birth weight babies, they are transferred to such facilities as soon as possible.
- Once an infant's care needs reduce they should be transferred to the appropriate level of care.
- Neonatal units and transport services should be configured to allow the parents to remain in the unit with their baby.

**Care Providers:**

- Staff providing care for infants requiring neonatal services are welcoming and empower parents to bond with and care for their baby.
- Staff working in neonatal units receive appropriate training in methods to improve family centred-care.
- There is an adequate provision of nursing staff and consultant cover to provide the nurse: infant ratios outlined in the Department of Health Toolkit.
- All staff including should be given training in supporting women to breastfeed.

## 1.0 Aim

The aim of this rapid review was to distil core principles and practice recommendations that can lead to effective, equitable, sustainable and acceptable care provision for babies requiring neonatal services and their families; both for extremely premature, very low birth weight or very sick babies, and for babies who require additional care but who are not so vulnerable. More specifically:

- What is the optimal model of care (i.e. the overarching design, categories of practice and values and philosophy? of the service)?
- What is the optimal approach to organisation of care (i.e. whether or not services are regionalised, network approaches, staffing and early supported discharge)?
- What are the essential characteristics of care providers (i.e. interdisciplinary working, education and training)?

This review will examine neonatal care provision for babies with different requirements as follows:

- Models of care and service configuration for extremely preterm (EP), very preterm (VP), extremely low birth weight (ELBW), very low birth weight (VLBW) or very sick babies and their families. This will consider family engagement in the care of their baby, centralisation of neonatal intensive care facilities, and networks for the provision of neonatal care.
- Models of care and service configuration for babies who require additional care but are not so vulnerable, and their families. This will consider family engagement in the care of their baby, transitional care, and early supported discharge.

## 2.0 Methods

A rapid evidence review was undertaken by identifying systematic reviews, key primary studies and guidance considering the evidence on centralisation of neonatal services, and identifying examples of good practice. The protocol for the review is detailed in table 1.

Table 1. Rapid Review Protocol.

	<b>Details</b>	<b>Additional Comments</b>
Rapid Review questions	<ol style="list-style-type: none"> <li>1. What recommendations can be made regarding the optimal model of care for:                             <ol style="list-style-type: none"> <li>a. very preterm, extremely preterm, very low birth weight, extremely low birth weight or very sick babies and their families?</li> <li>b. babies who require additional specialist care but are not so vulnerable, and their families?</li> </ol> </li> <li>2. What recommendations can be made regarding organisation of care and care providers to provide effective, equitable, sustainable and acceptable care for:                             <ol style="list-style-type: none"> <li>a. very preterm, extremely preterm, very low birth weight, extremely low birth weight or very sick babies and their families?</li> </ol> </li> </ol>	<ul style="list-style-type: none"> <li>• Very preterm &lt;32 weeks, extremely preterm defined as &lt;28 weeks, very low birth weight is defined as &lt;1500g and extremely low birth weight is defined as &lt;1000g.</li> <li>• Babies who require additional specialist care but are not so vulnerable, can include late preterm infants, infants born to mothers with problems (e.g. diabetes, substance abuse), some congenital anomalies and babies with feeding problems/excess weight loss</li> <li>• Model of care is defined as the overarching design and values of the service.</li> </ul>

	<ul style="list-style-type: none"> <li>b. babies who require additional specialist care but are not so vulnerable, and their families?</li> </ul>	<ul style="list-style-type: none"> <li>• In terms of this review, service configuration is defined as types of unit, networks, early supported discharge and workforce configuration is defined as skill mix (i.e. roles of those providing care).</li> </ul>
Objectives	To distil core principles and practice recommendations that can lead to effective, equitable, sustainable and acceptable care provision for babies requiring neonatal services and their families; both for very or extremely preterm, very or extremely low birth weight or very sick babies, and for babies who require additional care but who are not so vulnerable.	
Language	English	
Study design	<ul style="list-style-type: none"> <li>• Systematic reviews of RCTs, cluster-controlled trials, quasi-randomised controlled trials, observational studies.</li> <li>• Systematic reviews of qualitative studies with mothers and their families, and/or healthcare professionals.</li> </ul>	If there is a lack of systematic reviews in this subject area then primary studies and then case studies will be sought by contacting experts and examining reference lists of non-systematic reviews and commentaries.
Status	Papers published in academic journals and reports published by NICE, RCOG, RCPH, RCM, RCN, BAPM, Department of Health and international equivalents	
Population	Infants requiring neonatal services and their families	
Intervention	<ul style="list-style-type: none"> <li>• For question 1a and 1b the intervention of interest includes strategies to engage the family in the care of their baby.</li> <li>• For question 2a the intervention of interest is centralisation of neonatal intensive care with essential supporting services.</li> <li>• For question 2b the intervention of interest is strategies to provide appropriate transitions of care and early supported discharge.</li> </ul>	<ul style="list-style-type: none"> <li>• Strategies to engage families in care of their baby include aspects such as care provision, skin-to-skin contact, rooming-in, breastfeeding and decision making.</li> <li>• Essential supporting services include neonatal transport services and all forms of assistance for parents (including accommodation, financial, psychological).</li> </ul>
Comparator	<ul style="list-style-type: none"> <li>• For question 1a and 1b the comparator would be a model of care that did not engage the family in the care of their baby (i.e. all or much of the care provided and decisions made by healthcare professionals).</li> <li>• For question 2a the comparator would be non-centralised and non-networked services.</li> </ul>	<ul style="list-style-type: none"> <li>• It is acknowledged that in some instances, there may be minimal engagement of parents and we will consider dose-response relationships. However, only situations in which the parents are involved as equal caregivers, will be</li> </ul>

	<ul style="list-style-type: none"> <li>For question 2b the comparator would be care as usual (i.e. remaining in the neonatal unit)</li> </ul>	<p>classed as a family engagement approach.</p>
Outcomes	<ul style="list-style-type: none"> <li>Infant survival to discharge from hospital</li> <li>Infant morbidity</li> <li>Length of stay in neonatal care setting</li> <li>Breastfeeding/breastmilk feeding rates</li> <li>Skin to skin care provision</li> <li>Wellbeing of families</li> <li>Families' views and experiences of services</li> <li>Staff views and experiences of services</li> </ul>	
Other criteria for inclusion/exclusion of studies	<ul style="list-style-type: none"> <li>No date limit</li> <li>Exclude conference abstracts</li> </ul>	
Review Strategies	<ul style="list-style-type: none"> <li>Cochrane Neonatal group will be searched. Following databases will be searched: MEDLINE, MIDIRS, HMIC, CINAHL. The websites of NICE, RCOG, RCM, RCN, BAPM, BFI and RCPH and the Department of Health will all be searched. The Scottish Government's consultation document will be examined. Subject experts will be asked to identify any additional studies not retrieved by the review.</li> <li>Data on all included reviews will be extracted into evidence tables.</li> <li>A narrative summary will be presented.</li> </ul>	
Critical Appraisal	<ul style="list-style-type: none"> <li>The NICE methodology checklist for systematic reviews and meta-analyses will be used to assess study quality for systematic reviews.</li> <li>Quality of clinical guidelines will be assessed using Greenhalgh's (2014) checklist for set of clinical guidelines.</li> </ul>	<p>Checklist by Greenhalgh is based partly on the AGREE criteria.</p>



## 3.0 Findings

### 3.1 Search results

This section provides a description of the records identified by each database or source and the selection process. The study selection process is illustrated in figure 3.1.

#### 3.1.1 NICE

All NICE guidelines (n=5) related to neonatal care were examined for relevance according to the inclusion/exclusion criteria detailed in Appendix 2. Only one guideline (on donor milk banks) that met the inclusion criteria was identified and included in the review (NICE, 2010a). In addition one quality standard on the provision of neonatal care was also examined (NICE, 2010b) and is included in the review and will be discussed in the narrative summary (see section 3.3.1.1).

#### 3.1.2 SIGN

No SIGN guidelines related to neonatal care were identified.

#### 3.1.3 Cochrane Neonatal group

Titles and abstracts were all screened for relevance to neonatal care provision (i.e. reviews which appeared focused on specific clinical management aspects were excluded). On the basis of this, six articles (detailed in Appendix 2) were retrieved for further examination and five were included in the review. These will be detailed in the narrative summary, however, as they were also identified in the database search of systematic reviews, they will be discussed in this section.

#### 3.1.4 Database search

MEDLINE, CINAHL, MIDIRS and HMIC were searched using a combination of index and free-text terms relevant to neonatal care. In addition systematic review filters were added to the CINAHL and MEDLINE searches. See Appendix 1 for the full search strategy.

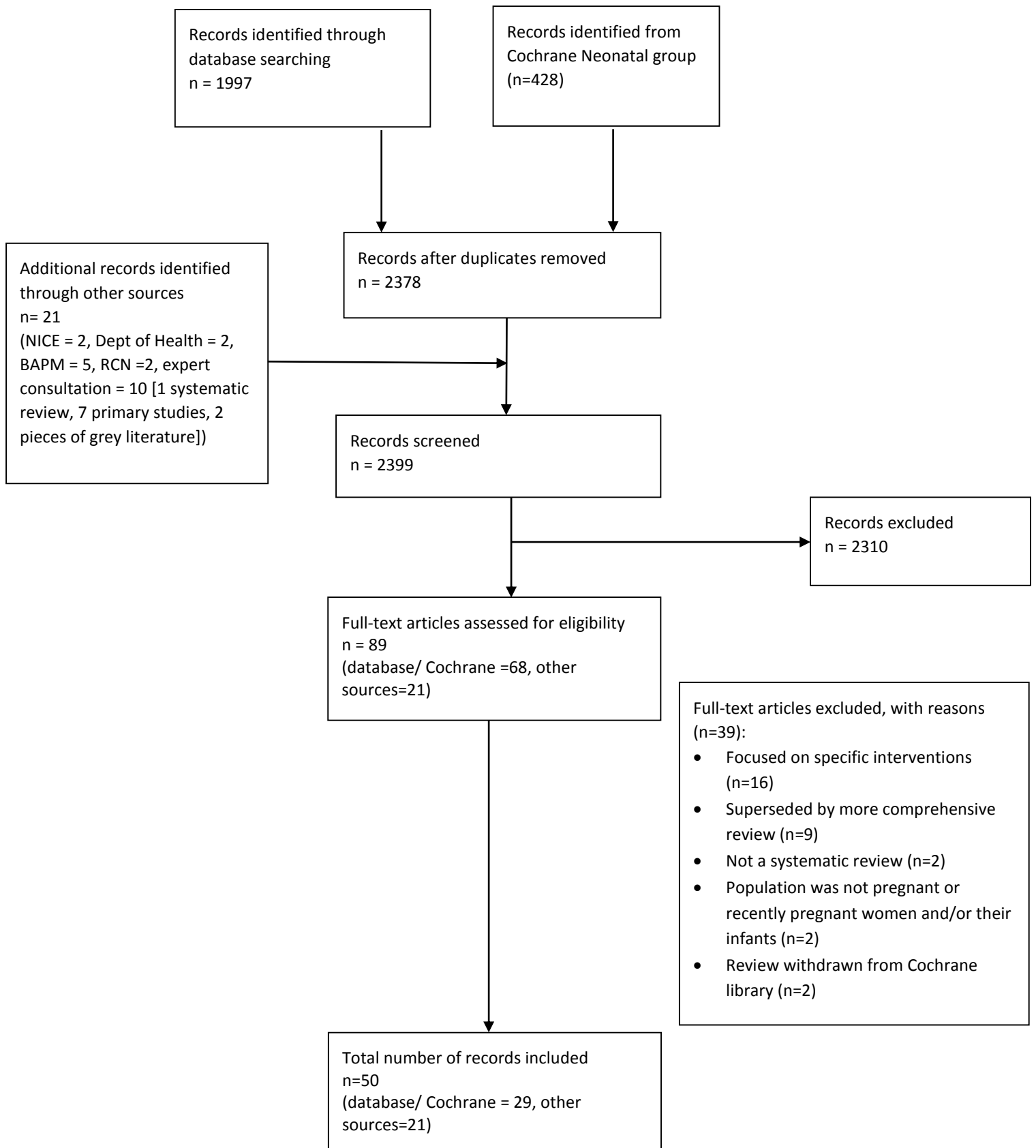
A total of 1955 records were identified after de-duplication. Following title and abstract screening 68 potentially relevant articles were retrieved for full text screening and 39 of these were excluded for the following reasons: not a systematic review (n=17), not focused on neonatal care provision (n=12), not in English (n=4), excluded neonates (n=1) or was no longer available/no access (n=5). The remaining 29 met the inclusion criteria and are included in this rapid review and detailed in section 3.3.1.1.

In addition to systematic reviews, the database search also identified a number of primary studies. Whilst this rapid review aimed to focus on systematic reviews, there was insufficient data from the included systematic reviews on regionalisation of neonatal care that could be applied to a Scottish context. Therefore key primary studies (n=7) which were identified in the search will also be included and discussed in the narrative synthesis.

#### 3.1.4 Department of Health

The Department of Health (DoH) was searched for guidance documents with the term neonatal in the title. Five records were returned but only one contained information specific to neonatal care provision, specifically a neonatal unit planning and design document (Dept. of Health, 2013). In addition the DoH Toolkit for High Quality Neonatal Services (NHS & Dept. of Health, 2009) was also

identified in the Scottish Government consultation. Both of these documents will be considered in section 3.2.2.2



**Figure 3.1. Study selection process**

### 3.1.5 BAPM

The titles all of all BAPM publications were screened and any titles which appeared relevant to models of neonatal care and service configuration (n=14) were retrieved and examined for relevance to the review questions detailed in Appendix 2. Eight records (two of which were studies independent of BAPM and one of which was produced by the RCPH) provided potentially relevant information.

### 3.1.6 RCPH

All RCPH current publications with the subject term neonatology were screened for relevance (n=26), however, none met the inclusion criteria as they did not focus on models of care for infants requiring neonatal services or configuration of such services. However, the search did identify the National Neonatal Audit programme reports for England and Wales, which may provide some useful background reading but will not be considered further in this rapid review.

### 3.1.7 RCM

No additional guidelines identified.

### 3.1.8 RCN

RCN publications were searched using the following terms: neonatal, neonatology, preterm, premature and infant. This identified six publications which were reviewed for relevance (see Appendix 2) and two of these met the inclusion criteria and will be discussed in the narrative summary.

### 3.1.9 Baby Friendly Initiative

The Baby Friendly Initiative (BFI) standards includes standards for babies in neonatal reviews. These are described in the Guide to Baby Friendly Initiative Standards which is included in the review and discussed in section 3.3.2.5 (Unicef UK, 2012).

### 3.1.10 Scottish Government Consultation

The consultation resulted in a document which details a wide range of sources that were recommended by stakeholders. The document was searched for any additional material that had not been previously identified. The following additional documents were identified:

- Impact of managed clinical networks on NHS specialist neonatal services in England: population based study (Gale et al., 2012).
- The provision of neonatal services: Data for international comparisons (Hallsworth et al., 2008).

The Gale et al. (2012) document is a primary study and will therefore be discussed in section 3.3.1.2. The Hallsworth et al. (2008) document is produced by the RAND Corporation and describes the provision of neonatal services in Scotland, Wales, Northern Ireland, the USA, Canada, Sweden and Australia. In essence it is a compendium of data and will not be considered further in the context of this rapid review, but it is detailed here as a resource for consultation.

### 3.1.10 English Maternity Services Review reports

The four reports produced for the English Maternity Services Review were examined, namely:

- Report 1: Summary of the evidence on safety of place of birth; and implications for policy and practice from the overall evidence review (Kurinczuk et al., 2015)

- Report 2: Perinatal and maternal outcomes by parity in midwifery-led settings: secondary analysis of the Birthplace in England cohort comparing outcomes in planned freestanding and alongside midwifery unit births (Hollowell et al., 2015a)
- Report 3: Systematic review and case studies to assess models of consultant resident cover and the outcomes of intrapartum care; and two international case studies of the delivery of maternity care (Knight et al., 2015)
- Report 4: A systematic review and narrative synthesis of the quantitative and qualitative literature on women's birth place preferences and experiences of choosing their intended place of birth in the UK (Hollowell et al., 2015b)

Neonatal care provision was not detailed any of the English review reports, which was focused on delivery of care in obstetric units compared to midwife-led units.

#### *3.1.11 Consultation with experts*

Review sponsors who are experts in the field of neonatal care, were asked to identify any additional highly relevant, key studies that the review did retrieve. One additional systematic review on interventions for preterm infants and their families was identified (Benzies et al., 2013) and is discussed in section 3.3.1.1.3. One additional rapid review on breastfeeding/breastmilk feeding in neonatal units conducted by NHS Health Scotland was also identified (NHS Health Scotland, 2016) and will be discussed in section 3.3.1.1.3. An additional six primary studies were identified. One of these studies examined the effect of volume of VLBW deliveries and neonatal unit level of care on neonatal morbidity and mortality and is discussed in section 3.3.1.2 (Jensen and Lorch, 2015), one examined the effect of centralisation of perinatal care in Denmark (Hasselager et al., 2016), one examined the association between hospital size and birth/health outcomes (Hemminki et al., 2011) and another three examined workforce configuration and are discussed in section 3.3.1.2 (Hamilton et al., 2007, Rogowski et al., 2013, Watson et al., 2016).

### 3.2 Overview and nature of included evidence

A total of 30 systematic reviews were identified from the Cochrane Neonatal Group and the Database Search. An additional rapid review conducted by NHS Health Scotland on breastfeeding/breastmilk feeding in neonatal units was also identified (NHS Health Scotland, 2016). These reviews were broadly divided into the following categories: parents' views and experiences of neonatal care units (n=11); methods for improving family-centred care (n=11); service configuration (n=5), transitional/discharge care (n=3) and workforce configuration (n=1). The reviews of parents' views and experiences took the form of meta-syntheses and were generally of a low quality. The reviews in other categories were primarily quantitative in nature and were generally of an adequate quality. The data extraction tables for each included systematic review are detailed in Appendices 3.1-3.5 and the critical appraisal for each included study is detailed in Appendix 4.

The thirteen included primary studies on workforce and service configuration were quantitative observational studies, which leaves them susceptible to bias.

The systematic reviews and primary studies provide evidence that can help inform practice and will be summarised in section 3.3.1. In addition, a number of guidelines and standards were identified from NICE, Department of Health, BAPM, BFI and RCN. Whilst these are primarily based upon non-systematic reviews and consensus statements, they are currently used in practice and provide some practical advice on the provision of neonatal care and will therefore be summarised in section 3.3.2.

### 3.3 Narrative Summary

A summary of each of the identified documents will now be presented.

#### 3.3.1 Database Searches (including Cochrane Neonatal Group)

##### 3.3.1.1 Systematic Reviews

###### 3.3.1.1.1 Families views and experiences

The reviews of parents' views and experiences took the form of meta-syntheses, eight of which were judged as being low quality (Aagaard and Hall, 2008, Alves et al., 2013, Cleveland, 2008, De Rouck and Leys, 2009, Obeidat et al., 2009, Renata Ribeiro et al., 2015, Rosenstock and van Manen, 2014, Swartz, 2005), primarily due to lack of critical appraisal and lack of detail of methods of synthesis (see Appendix 4 for individual critical appraisal tables). The other three reviews were of adequate quality (Butt et al., 2013, Provenzi and Santoro, 2015, Sisson et al., 2015), although some of the individual studies were poor quality. It should also be noted that there was considerable overlap between the reviews in terms of included studies. Full details of the characteristics of the reviews and their results are presented in Appendix 3.1 and a summary of this information will now be presented.

The individual studies included in the reviews contained studies from a range of countries including the USA, UK, Sweden, Australia, Denmark, Canada, South Africa, the Netherlands, Israel, Thailand, Finland, Brazil, Hong Kong, Norway, Iran, France and Portugal. However, there were more studies from the USA than any other country. Whilst the majority of reviews included studies on both parents, the majority of data in the included studies was from mothers. However, two reviews specifically focused on fathers' experiences (Provenzi and Santoro, 2015, Sisson et al., 2015). Only one review (Rosenstock and van Manen, 2014), focused on a specific vulnerable group, namely adolescent parents.

Appendix 3.1 provides full details of the themes identified in each review, however, the following themes recurred across the reviews:

- Mixed feelings of relief and fear/worry and needing to watch over infant (Aagaard and Hall, 2008, Cleveland, 2008, Obeidat et al., 2009, Provenzi and Santoro, 2015, Renata Ribeiro et al., 2015, Swartz, 2005)
- Upset at not getting to know the baby, feeling excluded from the baby's care and feeling need for permission to care for the baby (Aagaard and Hall, 2008, Cleveland, 2008, Provenzi and Santoro, 2015, Sisson et al., 2015)
- Not feeling like a "normal" mother and delay in maternal identity (Aagaard and Hall, 2008)
- Initial feelings of being overwhelmed in the NICU environment (noise, equipment) but then feeling more comfortable as become more familiar with the environment (Aagaard and Hall, 2008)
- Nurses can be seen as "gatekeepers" who mediate the relationship between parents and baby (Aagaard and Hall, 2008, Cleveland, 2008, Renata Ribeiro et al., 2015):
  - Facilitative nursing actions include being kind, helpful, supportive, answering questions, reassuring and helping the mother get to know her child
  - Inhibitive nursing actions include being ignorant and not respecting the infant's needs. Established relationships make asking questions easier
- Lack of continuity of care can impede on development of positive relationship with nursing staff (Aagaard and Hall, 2008)

- Facilitators to breastfeeding included (Aagaard and Hall, 2008, Alves et al., 2013): providing a sense of normality, sense of contributing to infants' development, opportunity to connect with infant, peer counsellors, support from staff, perception of NICU as comfortable and sterile supplies.
- Barriers to breastfeeding included (Alves et al., 2013): difficulties pumping, worries about milk supply, stressful nature of NICU, lack of privacy, lack of structured feeding routine and lack of role models and/or social support, isolation and competing time demands
- Communication and positive relationships with health care providers was crucial to parents' satisfaction with care (Aagaard and Hall, 2008, Butt et al., 2013, Cleveland, 2008, Renata Ribeiro et al., 2015) and can be facilitated through chatting which allows the nurse share expertise/knowledge in a manner that develops a collaborative relationship
- Information needs decrease over time as parents learn the NICU environment and their baby's needs (De Rouck and Leys, 2009)
- Feeling out of control (Obeidat et al., 2009, Provenzi and Santoro, 2015)
- Fathers feel like an outsider and need to be recognised as a father rather than just the mother's partner (Provenzi and Santoro, 2015, Sisson et al., 2015)
- Sense of parenthood develops through the NICU journey and helped through interaction with the baby (e.g. through kangaroo care) (Provenzi and Santoro, 2015, Sisson et al., 2015)

From these reviews we can distil some core principles as to how to provide care that takes the needs of the parents into account and is satisfactory to them. Specifically, the need for good, clear, empathetic communication from staff that enables parents to ask questions and feel more knowledgeable about their baby's condition and needs, and the neonatal care environment. In addition staff need to ensure that parents do not feel like outsiders and are positively encouraged and supported to participate in their baby's care and decision making processes. Specific aspects of care such as breastfeeding and kangaroo care can create a sense of normality and allow interaction with the baby and allow parents to take on the identity of being a parent. Specific to adolescent parents, Rosenstock and van Manen (2014) reported that adolescent parents were more withdrawn and less likely to ask questions. There is therefore a need for additional efforts from health professionals to empower adolescent parents in a NICU setting. Many of the needs of parents identified can therefore be met with a family centred model of care and evidence for approaches that can be taken to facilitate this will be detailed in 3.3.1.1.3.

#### 3.3.1.1.2 Service Configuration

The reviews related to service configuration were primarily focused on regionalization of care and also neonatal transport. The reviews of regionalization of care were reviews of quantitative studies, one of which was judged as high quality (Chang et al., 2015), three of which were judged as adequate (Lasswell et al., 2010, Mori et al., 2007, Rashidian et al., 2014) and one of which was judged as low quality (Neogi et al., 2012). However, it should be noted that the review by Chang et al. which was a Cochrane review looking at specialist teams for neonatal transport did not identify any randomised (including cluster-randomised) or quasi-randomised trials, highlighting a need for research in this area. Additionally, the review by Mori et al. only included one study which was conducted in India and therefore may not be applicable to the Scottish context and will also not be discussed further.

Rashidian et al. (2014) aimed to assess the effectiveness of perinatal regionalization on improving maternal and neonatal health outcomes. A total of eight studies were identified: six studies included all births between particular time periods; one study specifically looked at very preterm and one specifically looked at very low birth weight (VLBW) infants. Studies took the form of interrupted time

series (n=3); controlled before-and-after (n=1); uncontrolled before-and-after (n=4). Six studies were conducted in the US, one in Canada and one in France. It should also be noted all studies were published prior to 1990. A narrative synthesis was provided and indicated that there were some improvements in neonatal mortality, perinatal mortality, low birth weight, still birth, fetal mortality, infant mortality, low five minute Apgar score, motor development and maternal sensitivity and satisfaction. However, each outcome was generally only evaluated by a small number of studies and results did not consistently reach statistical significance (see Appendix 3.2 for further details). However, although the systematic review itself was conducted to an adequate standard, five of the included studies were at high risk of bias and these results must therefore be interpreted with caution.

Lasswell et al. (2010) aimed to evaluate published data (in the form of randomized controlled trial, prospective cohort, retrospective cohort, and case-control study designs) on associations between hospital level at birth and neonatal or pre-discharge mortality for VLBW and very preterm (VPT) infants. The review identified 37 studies for VLBW and 4 studies for very preterm infants. The majority of studies were from the USA (n=22) and the other studies were conducted in Canada, Ghana, Israel, Australia, and Europe. Only studies deemed as being of adequate quality based upon the level of adjustment for confounding and description of level of care designations and/or hospital care capabilities were included in the meta-analysis (VLBW/ELBW, n=9; preterm, n=3). For VLBW infants a 60% increase in neonatal mortality was reported for those not born at a level III hospital. For ELBW infants this increased to 80% increase for those not born at a level III hospital (full details provided in appendix 3.2). For very preterm babies 42% increase in neonatal mortality for those not born at a level III. Whilst this supports level III care for VLBW and very preterm infants, the results should be treated with caution. First, the meta-analyses for VLBW and extremely LBW infants showed significant heterogeneity, secondly the meta-analysis for pre-term infants only included three studies, thirdly a formally identifiable risk of bias tool was not utilised in the critical appraisal process and finally the majority of studies were conducted in the US and may not be applicable to the Scottish context.

The one low quality review by Neogi et al. (2012) identified 17 observational and interventional studies which assessed different factors that affect effectiveness of facility based newborn care on neonatal outcomes (including regionalization of care). Neogi et al. reported that regionalization increased the in-utero transfer of high risk newborns and improved survival chances especially of VLBW infants which led to a reduction in neonatal mortality. In addition, high patient volume (>2,000 deliveries/ year), inborn status, availability of referral system and inter-facility transfers, and adequate nursing care staff in neonatal units also demonstrated protective effect in averting neonatal deaths. However, it must be stressed that this is a low quality review and no formal critical appraisal tool was used to examine risk of bias in the included studies.

Whilst these systematic reviews do provide some support for regionalization of care for the most vulnerable babies, as detailed, they have a number of considerable limitations. In addition, such an approach would need to include arrangements for transfer back to more regionalized units providing lower levels of care when appropriate to ensure parental contact is not impeded by having to travel large distances. Due to the importance of this area in the review and the apparent lack of good systematic review level evidence, pertinent primary studies are discussed in 3.3.1.2.

#### 3.3.1.1.3 Methods for Improving Family Centred Care

Out of the ten systematic reviews that examined possible methods that could improve family centred care, seven were of quantitative studies (Benzies et al., 2013, Conde-Agudelo et al., 2014, Gray and Flenady, 2011, Johnston et al., 2013, Koh et al., 2005, Renfrew et al., 2009, Shahheidari and

Homer, 2012), two were reviews of qualitative studies (Chan et al., 2016, Kearvell and Grant, 2010) and two records reported on the same review which was conducted as part of the POPPY study and included both quantitative and qualitative studies (Brett et al., 2011, Staniszewska et al., 2012). The rapid review on breastfeeding/breast milk feeding in neonatal units included systematic reviews and qualitative studies on the experiences of parents and NICU staff (NHS Health Scotland, 2016)

Of the reviews of quantitative studies, two were high quality Cochrane reviews examining Kangaroo Care (Conde-Agudelo et al., 2014; Johnston et al., 2014), one was a high quality Cochrane review that assessed the usefulness of providing parents of sick babies with audiotape recordings of their consultations with neonatologists, one was a high quality HTA review that examined interventions that promote or inhibit breastfeeding or feeding with breastmilk for infants admitted to neonatal units (Renfrew et al., 2009), one was a high quality Cochrane review that assessed effects of cot-nursing versus incubator care on temperature control and weight gain in preterm infants (Gray & Flenady, 2011) and one was a high quality review that examined early intervention programmes for preterm infants and their families. Koh et al. identified no studies and this review will therefore not be discussed further. Shahheirdari and Homer conducted a low quality systematic review which aimed to describe the main features of NICU design and determine the advantages and limitations of the design in terms of outcomes for babies, parents, and staff. Finally, the review conducted as part of the POPPY study (Brett et al., 2011, Staniszewska et al., 2012) examined interventions for communicating with, supporting and providing information for parents of preterm infants which was graded as low quality.

Conde-Agudelo et al. (2014) identified 18 RCTs on the use of kangaroo care for stable LBW infants as an alternative to conventional neonatal care. The authors reported that the evidence (which was mixed in quality) supported kangaroo care in terms of significant decreases in mortality, nosocomial infection, hypothermia, length of stay in hospital, severe infection/sepsis, weight, head circumference, and length gain, breastfeeding, mother satisfaction with method of infant care, some measures of maternal-infant attachment, and home environment (see Appendix 3.3 for further details). It should be noted that the duration of Kangaroo Care was hugely variable but tended to be less than two hours in the high income countries, so it is plausible that more extended periods of Kangaroo Care may confer to greater benefits in terms of outcomes. Johnston et al. (2014) also examined the use of kangaroo care but in the context of reduced procedural pain for stable infants. Nineteen randomised or quasi-randomised controlled trials were included and were of mixed risk of bias and due to heterogeneity only a small number of studies (maximum four) were including in each analysis, so it is difficult to draw strong conclusions. However, the studies tended to favour skin-to-skin care or were non-significant.

Renfrew et al. (2009) identified 48 studies (31 of which were RCTs) and were conducted in a range of countries: Malaysia, India, USA, Australia, Mexico, USA, Ecuador, UK, Colombia. Seven studies were rated as good quality, 28 as a moderate quality and 13 as poor quality. The review found strong evidence that short periods of kangaroo care (up to 1hr) increased the duration of breastfeeding up to 1 month post discharge. There was also evidence that simultaneous pumping with an electric pump has advantages in the first two weeks. Strong evidence was found for peer support delivered at home or in hospital. BFI accreditation was also associated with an increase in number of infants receiving any breastmilk (see Appendix 3.3 for further details).

Gray and Flenady (2011) identified five RCTs which were conducted in low/middle and high income countries. The authors reported that there was no significant difference in temperature control and weight gain when a heated water filled mattress was used instead of an incubator. However, when warming of the nursery was used weight gain was significantly smaller in the cot group at week one



only (see Appendix 3.2 for further details). However, the authors do caution that although included studies were low risk bias, only 247 infants were included and further research is needed in this area.

Benzies et al. (2013) identified 18 RCTs (11 of which were included in the meta-analysis) which were conducted in the US, Australia, Japan and a range of European countries. The authors reported significant positive intervention effects for maternal anxiety, depressive symptoms, self-efficacy and sensitivity-responsiveness (see Appendix 3.2 for details) but not for stress. However, it should be noted that there was high levels of statistical heterogeneity in each analyses. This may be representative of the fact that interventions took the form of psychosocial support, education interventions and developmental interventions delivered by parents. Interestingly the authors concluded that no one intervention component was associated with consistent improvements in outcomes.

Shahheidari and Homer (2012) identified 12 studies (1 RCT, 4 prospective comparative studies, 3 before-and-after studies, 3 cross-sectional/descriptive studies and 1 qualitative study) which were mainly conducted in the US (but also Turkey, Sweden, Taiwan and Denmark). The authors reported that single family rooms were associated with decreased risk of infection, a shorter stay within the NICU and increased feelings of privacy by the family. However, they were reported to be harder to manage by nursing staff. It should also be noted again that this was a poor quality with no critical appraisal and also did not report significance levels of the included studies.

The POPPY study (Brett et al., 2011, Staniszewska et al., 2012) which was judged as low quality due to a lack of reporting on critical appraisal, identified a range of interventions such as behavioural assessment, individualised developmental and behavioural care programme (e.g. the COPE, NIDCAP, MITP and NCATs programmes), breastfeeding, kangaroo care, home support and communication with staff, that can be utilised to help parents with a child receiving neonatal care. The majority of RCTs identified were of individualised developmental and behavioural care programmes evaluated (n=9) and Brett et al. reported that these helped reduce maternal stress and improved parental understanding and interaction. Limited RCT evidence was available for the other interventions (see Appendix 3.3 for further details). It should also be noted again that this review was of a low quality due to inadequate critical appraisal and limited material identified by the search.

The rapid review conducted by NHS Health Scotland (2016) aimed to summarise the best available evidence about breastfeeding/breast milk feeding in neonatal units and to understand the experiences of parents of NNU babies and the staff caring for them. The review identified eight systematic reviews and 17 primary qualitative studies. The findings from the included studies were grouped in the following themes by family and staff perspectives and summarised table 3.1

In addition, the review (NHS Health Scotland, 2016) also reported evidence that estimated that by increasing the number of babies being breastfed on discharge from 35% to 50% could potentially save £2.3 million in the treatment of necrotising enterocolitis. This would increase to £6million for a rate of 75% and £10 million for a rate of 100%.

It should be noted, that there was overlap in the studies identified in the review by NHS Health Scotland and this rapid review. In addition, no description of any critical appraisal process was provided, making it difficult to judge the quality of the included studies and reviews, not already included in this rapid review.

**Table 3.1 Summary of NHS Health Scotland rapid review on breastfeeding and breastmilk feeding in neonatal units**

	Family Perspectives	Staff Perspectives
<b>The impact of premature delivery</b>	<ul style="list-style-type: none"> <li>Mothers felt different and did not have a sense of normality as babies were not with them. This was worsened in the case the mother was also unwell.</li> <li>Mothers felt a loss of autonomy of their own behaviour and establishing a relationship with the baby</li> <li>Mothers felt anxious at not being able to care for or access their baby</li> </ul>	<ul style="list-style-type: none"> <li>Staff felt the NICU's role was to provide specialist clinical care</li> <li>Difficult to implement BFHI due to lack of rooming-facilities and the time needed to initiate and establish breastfeeding. Lack of funding and resources compounded this.</li> <li>Mothers and babies lived in 'separate worlds'</li> <li>Lack of staff confidence in advocating breastfeeding in favour of formula feeding</li> <li>Lactation consultants and staff training had improvements on staff knowledge, attitudes and behaviour</li> </ul>
Adapting to the neonatal environment	<ul style="list-style-type: none"> <li>Parents values consistent and clear information, receiving emotional support and practical guidance for feeding their baby</li> <li>Continuity of care was very important to parents</li> <li>Lack of privacy and 'homeliness' could impede breastmilk expression and make them feel like visitors</li> </ul>	No data reported
Importance of breastmilk and expressing	<ul style="list-style-type: none"> <li>Helped mothers felt they were doing something beneficial for their baby</li> <li>Enabled mothers to continue the biological connection which began in pregnancy</li> <li>Some mothers found expressing milk degrading</li> <li>Transporting expressed milk could be an issue for some mothers who depended on public transport or lifts from other people</li> <li>Being separated from the baby could reduce the stimulation that mothers need to stimulate the milk supply</li> </ul>	No data reported
Mothers' motivation to breastfeed/ breast milk feed in the neonatal unit	<ul style="list-style-type: none"> <li>Understanding of the benefits encouraged women to breastfeed</li> <li>Delays in expression and concern about supply acting as barriers. Particularly in terms of anxiety around weight gain and if expressed breast milk was left in public view.</li> <li>Staff support crucial in learning to understand feeding techniques and cues</li> <li>Conflicting advice acted as a barrier</li> </ul>	<ul style="list-style-type: none"> <li>Transitions to oral feeding were based on staff experience and were inconsistent</li> <li>Information used to calculate volume of feed necessary was unclear and could result in some babies being overfed</li> <li>Continuous increase in prescribed milk could add pressure to mothers who would be demoralised if this</li> </ul>

		<p>needed to be supplemented with formula</p> <ul style="list-style-type: none"> <li>• Feeding practices when the mother was not available varied between units</li> </ul>
<p>Coping strategies in response to breastfeeding/ breast milk feeding in the neonatal unit</p>	<ul style="list-style-type: none"> <li>• Mothers developed a sense of resilience in response to their fears and anxieties</li> <li>• Trial and error approaches were used to overcome feeding problems.</li> <li>• Learning from others and health professional support was important for improving self-efficacy</li> </ul>	<ul style="list-style-type: none"> <li>• Nurses highly motivated to maximise the potential of NICU babies</li> <li>• A general spirit of camaraderie and reciprocal willingness to help out was highly valued</li> <li>• High attention to detail necessary due to the small margins of safety when caring for a fragile infant</li> <li>• Technology and technical skills viewed as integral to providing care for the sickest babies. This can lead to a disproportionate focus on the technical aspects of the baby's care</li> </ul>
<p>Peer support in the neonatal unit</p>	<ul style="list-style-type: none"> <li>• Peer support helped give mothers hope and reduced their sense of isolation</li> <li>• Helped mothers cope and preserve with breastfeeding</li> <li>• Helped 'normalise' the experience and provide accessible information</li> </ul>	<ul style="list-style-type: none"> <li>• Staff considered peer counsellors as assets who could provide unique support.</li> <li>• Helped lighten staff load</li> <li>• Staff could take the opportunity to learn from them</li> </ul>
<p>The need to get home</p>	<ul style="list-style-type: none"> <li>• Getting home seen as a step toward establishing 'normality' and gaining control</li> <li>• Some mothers lacked confidence and were anxious about going home</li> <li>• Readiness for going home was associated with feelings of having developed a close relationship with the baby and feeling they are the sole carers.</li> <li>• Some parents perceived staff support as interrupting and/or intruding on normal parent-infant bonding</li> <li>• The requirement for successful feeding for discharge could lead to some mothers choosing to bottle feed instead</li> </ul>	

In addition, the review (NHS Health Scotland, 2016) also reported evidence that estimated that by increasing the number of babies being breastfed on discharge from 35% to 50% could potentially save £2.3 million in the treatment of necrotising enterocolitis. This would increase to £6million for a rate of 75% and £10 million for a rate of 100%.

It should be noted, that there was overlap in the studies identified in the review by NHS Health Scotland and this rapid review. In addition, no description of any critical appraisal process was provided, making it difficult to judge the quality of the included studies and reviews, not already included in this rapid review.

Of the qualitative reviews, one was a low quality review which examined how nurses can support the mother-infant dyad within the neonatal intensive care unit (Kearvell and Grant, 2010), one was a low quality review examining barriers to kangaroo care (Chan et al. 2015). Kearvell and Grant (2010) reported that mother-infant interaction can be supported through kangaroo care, breastfeeding and participation in routine care, whereas mother-nurse interaction is improved through providing psychosocial support and good communication. Given the positive findings from the systematic reviews about Kangaroo care, it is important to consider the barriers to this practice. Chan et al. reported that staff buy-in, time and prioritisation are key to implementing Kangaroo care. In addition aspects of the care setting such as space, accommodation for parents and lack of privacy, as well as fear of harm to the baby can deter the parents from engaging in kangaroo care.

#### 3.3.1.1.4 Transitional Care /Early Discharge

One review specifically examined early discharge (Collins et al., 2015) and two examined transitional care (Lopez et al., 2012, Miah, 2013). Collins et al. (2015) conducted a Cochrane review which aimed to determine the effects of a policy of early discharge of stable preterm infants with home support of gavage feeding compared with a policy of discharge of such infants when they have reached full sucking feeds. Although this was a high quality review, only one study was identified, which reported a significantly reduced hospital stay and risk of infection in early discharge infants who were relatively mature. There was no significant difference between groups in terms of breastfeeding, weight gain or re-admission in first 12 months post-discharge home, mortality, confidence in handling baby at time of discharge, preparedness to take responsibility for the care of the infant or anxiety. Whilst this is encouraging the study only consisted of 88 infants (see Appendix 3.4 for further details). Therefore, the lack of studies indicate a need for further research in this area. It should also be noted that some of the programmes for parents that were included in the systematic reviews (e.g. Brett et al., 2011 Staniszewska et al. 2012) on programmes for parents for promoting family centred care also aimed to promote early discharge (see Appendix 3.2 for details). Both the reviews by Lopez et al. (2012) and Miah (2013) aimed to examine the impact of transitional care. Both studies included quantitative and qualitative evidence, and were judged to be low quality. Lopez et al. identified seven studies which reported that communication between the families at home and care providers, home visits, educational groups, nurse involvement and videoconferencing were important components of transitional care. It should be stressed that the review by Miah et al. was very poor. The majority of studies are unpublished and descriptive but described as being of high quality. Despite positive effects being reported no effect sizes or measures of significance are detailed and this review will therefore not be considered any further.

#### 3.3.1.1.5 Workforce Configuration

Only one review on workforce configuration was identified (Sherenian et al., 2013). This was an adequate quality review which aimed to determine how nurse-to-patient ratios or nursing workload affects outcomes in the NICU. Six observational studies from the US, UK, Australia and South America were identified. The authors report that three studies reported low nurse-patient ratio was associated with higher mortality and one was associated with lower mortality. However, caution should be used in interpreting these results as the included studies were considered to have high risk of bias and the cut-off for low ratio was defined differently in different studies (see Appendix 3.5 for further details).

#### 3.3.1.2 Additional Primary Studies

Thirteen additional primary studies which were identified in either the database search or through consultation with experts were included in the review. Eight studies contained data pertinent to service configuration. Specifically, four studies examined the impact of place of birth in terms of size of hospital, level of unit and activity levels of units on neonatal outcomes (Hemminki et al., 2011,

Jensen and Lorch, 2015, Marlow et al., 2014, Watson et al., 2016). Four studies examined the impact that regionalization of neonatal units has on place of birth (Blondel et al., 2009, Gale et al., 2012, Hasselager et al., 2016, Zeitlin et al., 2004) and one study simulated how regionalization would impact upon staffing numbers and parent travel time (Allen et al., 2015). Four studies contained data pertinent to workforce configuration in terms of the impact of staffing numbers on neonatal outcomes.

#### 3.3.1.2.1 Primary Studies on Service Configuration

First, the EPICure 2 (Marlow et al., 2014) study examined the effect of place of birth on perinatal outcomes within a prospective cohort of births (22-26 weeks gestation). Marlow et al. reported that 56% of these infants were born in a facility with level III services and 34% with level II services. Birth in a level III facility was associated with a reduced risk of death (adjusted OR 0.73, CI 0.59-0.90), although there was no significant difference in the proportion surviving without neonatal morbidity (adjusted OR 1.27, CI 0.93-1.74). Note odds ratio adjusted for gestational age and birthweight for gestation. In terms of antenatal transfer, infants who were born to mothers who were not transferred from a level II service to level III service had an increased risk of death (adjusted OR 1.44, CI 1.09 -1.90). Babies of women who were booked into level III services had a reduced risk of mortality compared to babies of women who were booked into level II services (OR 0.79, CI 0.63-0.98). There were no differences in mortality rates between infants who were transferred postnatally compared to those who remained in level II or III services. Further analysis looked at the impact of the activity level of the service on neonatal survival and identified that units with higher activity had fewer deaths overall (OR 0.68, CI 0.52-0.89). Although this is an observational study and there are risks of bias from a number of confounders, it is a very complete cohort (containing all babies delivered in England and Wales in 2006) which was conducted relatively recently in a UK system where centralisation was not well developed. The data therefore do potentially provide some evidence for infants born between 22 and 26 weeks to be managed in level III units with higher levels of activity.

Secondly, Watson et al. (2014) also conducted a retrospective, population-based analysis of 20554 infants born <33 weeks between 2009 and 2011 and admitted to neonatal units in England, to examine the effects of designation and volume of neonatal care at the hospital of birth on infant mortality and morbidity in very preterm infants in a managed clinical network. There was no significant difference in neonatal mortality (i.e. 28 day mortality) for infants <33 weeks gestational age who were born at a tertiary neonatal unit compared to those not born at a tertiary unit (OR: 0.77, CI: 0.59-1.00), however, the difference was significant when only infants <27 weeks gestation (n=2559) were included in the analysis (OR: 0.65, CI: 0.46-0.91). There was also a significant difference in neonatal mortality for all infants <33 weeks cared for in a high-volume neonatal unit (OR: 0.73, CI: 0.56-0.95) and this was greater when the analysis was restricted to infants <27 weeks (OR: 0.62, CI: 0.44-0.87). The only significant difference in any in-hospital mortality was a reduced rate for infants <27 weeks born in a hospital with a high volume neonatal unit (OR: 0.71, CI: 0.52-0.97). There was a significant reduction in bronchopulmonary dysplasia (BPD; defined as a requirement for supplementary oxygen for at least 28 days and at 36 weeks postmenstrual age) in all infants <33 weeks born in a hospital with a tertiary neonatal unit (OR: 1.23, CI: 1.07-1.40). The effect was more pronounced when the analysis was restricted to infants <27 weeks (OR: 1.50, CI: 1.11-2.01). BPD was also significantly reduced in infants <27 weeks cared for in a high volume unit (OR: 1.59, CI: 1.18-2.14). There were no other significant differences in any other outcome (i.e. treatment for retinopathy of prematurity, surgery for necrotizing enterocolitis or post-menstrual discharge >40 weeks). It should be noted that this study does not separate out the effects for infants transferred to tertiary and high volume units and is observational in nature.

Jensen et al. (2015) aimed to assess the independent effects of a birth hospital's annual volume of VLBW and ELBW (defined by study authors as 500-1499g) infant deliveries and NICU level on composite neonatal morbidity-mortality outcomes in three US states (California, Missouri and Pennsylvania) between 1999 and 2009. Volume of VLBW infant deliveries were defined using the following categories:  $\leq 10$ , 11-25, 26-50, or  $>50$  deliveries per year. NICU levels were defined as: level II could provide basic well-newborn care; level IIA could resuscitate and stabilize preterm infants before transfer; level IIB could provide mechanical ventilation for  $<24$  hours or provide non-invasive positive airway pressure; level IIIA could care for infants born  $>28$  weeks gestation and weighing  $>1000$ g and airway support limited to mechanical ventilation; level IIIB could provide comprehensive care for infants  $<28$  weeks and had advanced respiratory support including high-frequency ventilation and inhaled nitric oxide; and level IIIC had all capabilities of level IIIB plus extracorporeal membrane oxygenation. Note that level IIIB and IIIC were combined in the analysis.

Jensen et al. (2015) reported that delivery at a hospital with ten or less VLBW infant deliveries per year was associated with the highest risk-adjusted odds ratios for death: (OR: 1.63, 95% CI: 1.35-1.96), death or severe interventricular haemorrhage (IVH; OR: 1.36, 95% CI: 1.14-1.36), and death or necrotizing enterocolitis (NEC; OR: 1.33, 95% CI: 1.12-1.57). There was no significant association between volume of VLBW deliveries and the risk of death or retinopathy (ROP) of prematurity but risk of death or bronchopulmonary dysplasia (BPD) was reduced in low volume units (OR: 1, 95% CI: 1.12-1.57). Delivery at a hospital with 11-25 VLBW infant deliveries per year was associated with the higher risk-adjusted odds ratios for death compared to hospitals with  $>50$  deliveries for death (OR: 1.25, 95% CI: 1.09-1.44) or death or severe interventricular haemorrhage (OR: 1.15, 95% CI: 1.01-1.33). There was no significant association between volume of VLBW deliveries and any of the other outcomes. Similarly, delivery at a hospital with 26-50 VLBW infant deliveries per year was associated with the higher risk-adjusted odds ratios for death compared to hospitals with  $>50$  deliveries for death (OR: 1.24, 95% CI: 1.12-1.38) or death or severe interventricular haemorrhage (OR: 1.15, 95% CI: 1.04-1.28). Again, there was no significant association between volume of VLBW deliveries and any of the other outcomes. Birth at a level I unit conferred an increased risk (compared to being born in a level IIIB/C unit) of death or BPD (OR: 1.38, 95% CI: 1.06-1.79) only. Risk of death or ROP was lower in the level I unit (OR: 0.73, 95% CI: 0.59 - 0.90). There was no significant association between level I centres and the other outcomes. Similarly, there was an increased risk of death or BPD and delivery in level IIA/B units (OR: 1.43, 95% CI: 1.13-1.82) but no association with any other outcome. Delivery at a level IIIA unit was associated with decreased risk of death or ROP (OR: 0.63, 95% CI: 0.49 -0.82). Whilst this is observational data and as such should be interpreted with caution, it is interesting as it suggests that the volume of deliveries is the stronger contributor to the risk of death, death or severe IVH, and death or NEC among VLBW infants.

Finally Hemminki et al. (2011) used data from the Finnish birth register from the period 1991-2008. The authors reported that rates of high risk births (defined as birthweight  $<1500$ g) born outside a university hospital decreased from 33% in 1991 to 17.1%. Unplanned out-of-hospital births were originally higher in the north of the country, however, due to an increase in unplanned out-of-hospital births in more densely populated areas the levels were similar from 2006-2009. After adjusting for birthweight perinatal mortality was lower in the university hospitals compared to large (adjusted OR: 1.63, 95% CI: 1.41-1.88), medium (adjusted OR: 1.96, 95% CI: 1.61-2.39) or small (adjusted OR: 1.53, 95% CI: 1.19-1.96) non-university hospitals. When the analysis was restricted to births  $>2500$ g there was no significant differences between hospitals. In addition the perinatal mortality rate was significantly higher for all unplanned out-of-hospital births (OR: 7.73, 95% CI: 4.94-12.12). There were no significant differences in perinatal mortality or neonatal care admissions

between babies born in the capital and those not born in the capital. However, there was a small increase in risk of caesarean section (adjusted OR: 1.08, 95% CI: 1.03-1.12) or mother in hospital for six days (adjusted OR: 1.24, 95% CI: 1.26-1.34). The authors suggest that this data indicates that small hospitals do not need to be closed on safety concerns if there is a regionalised system with a well-functioning referral system. However, it should be noted that there was some contamination on areas as some areas are served by multiple different level hospitals.

To assess the impact that reorganisation of neonatal services into managed clinical networks had on place of birth and having an acute or late transfer, Gale et al. (2015) conducted a population wide observational comparison on two cohorts before and after the establishment of managed neonatal networks. The cohorts included babies born at a gestational age of between 27+0 weeks and 28+6 weeks who were admitted to neonatal units. Specifically the first cohort included babies from 294 maternity and neonatal units in England, Northern Ireland and Wales (n=3522) and the second cohort included babies born in 146 units in England (n=2919). After reorganisation there was a significant increase in babies aged 27-29 weeks born in hospitals with the highest volume of neonatal specialist care (OR: 4.30, CI: 3.83-4.82). There was also an increase in survival in England in the second cohort (OR: 2.00, CI: 1.67-2.40). The number of late transfers back to a neonatal unit closer to home when stable also significantly increased from the first to second cohort (18% vs 22%,  $p < 0.001$ ). However, there was a significant increase in numbers of acute transfers to another hospital 24 hrs after birth (7% vs 12%,  $p < 0.001$ ), which as Gale et al. note, is associated with increased morbidity and mortality. It should also be noted that there was variation between the networks in the number of babies aged between 27+0 weeks and 28+6 born in hospitals with the highest levels of neonatal intensive care activity, however, not all networks provided data so there are some limitations with the data.

Evidence on the impact of regionalisation of neonatal care from outwith the UK is also reported in a comparison of two population-based cohorts in the Parisian region (Zeitlin, 2010) between 1997 (one year before regionalisation) and 2003 (five years after regionalisation). Preterm infants (24-31 weeks of gestational age) were significantly more likely to be born in a level III unit in 2003 than in 1997 (76.6% vs 67.2%,  $p = 0.001$ ), however when the analysis was restricted to infants 24-27 weeks the difference was not significant (69.3% vs 76.1%,  $p = 0.19$ ). There was a significant increase in antenatal corticosteroids administration for infants 24-31 weeks of gestational born in a level III unit (85.4% vs 94.0%,  $p < 0.001$ ), however, this was not significant when restricted to infants aged 24-27 weeks. There was also an increase in surfactant administration if admitted to the neonatal unit at 24-31 weeks (45.8% vs 54.0%,  $p = 0.028$ ) and at 24-27 weeks (78.2% vs 90.8%,  $p = 0.013$ ). There was a significant decrease in neonatal death in infants 24-31 weeks between 1997 and 2003 (adjusted OR: 0.66, CI: 0.46-0.95) but this was not significant when restricted to infants aged 24-27 weeks (OR: 0.68, CI: 0.40 – 1.14). There was also a significant decrease in IVH III and IV in infants aged 24-31 weeks (adjusted OR: 0.27, CI: 0.15-0.47) but no significant difference in bronchopulmonary dysplasia and periventricular leucomalacia. However, it should be noted there has been an advancement of fetal medicine that also occurred throughout the study and therefore the results should be considered with caution.

Additionally, the MOSAIC study (Blondel et al., 2009) studied the impact of organisation of obstetric service on the regionalisation of care for very preterm births (defined as 24-31 weeks gestation) across ten European regions (including the UK). The main outcome was the rate of births in a specialised maternity unit (defined as level III or a unit managing >50 very preterm admissions per year). Analysis of 490 000 live births showed that there was variation in the proportion of very preterm births in level III settings (63-93%) and that different methods contributed to higher levels

of regionalisation (including high proportion of total deliveries in specialised units, high proportion of in utero transfers or high proportion of women booked and managed at specialist unit during pregnancy).

Hasselager et al. (2016) examined the impact of centralisation of perinatal care in Denmark by comparing three cohorts of infants born at 22-28 weeks from 1994-1995 (n=183), 2003 (n=83) and 2011 (n=127). Following the implementation of centralisation in 1995, the delivery rates at level III NICUs increased from 69% to 87%. The ratio of infants who were transferred to level-3 NICUs almost doubled during the period. Overall survival increased during this period from 59% to 69% but this was statistically not significant. However, when the analysis was restricted to infants born before 26 weeks, survival significantly increased from 37% to 57% ( $p = 0.07$ ). The number of infants with IVH decreased significantly from 21% to 12% and the use of evidence based therapies also increased over this period. As this is an observational study confounding factors (including improvements in technology) may influence the results. In addition, the sample size is relatively small, nevertheless, this study suggests that centralisation may improve outcomes for the most vulnerable preterm babies (i.e. those born before 26 weeks).

In addition to the impact on neonatal outcomes, the effect that regionalisation has on service configuration and parents needs to be considered. Allen et al. (2015) developed a computer model which aimed to be able to predict nurse staffing, cost of service provision, number and distance of transfers, average travel distances for parents, and numbers of parents with an infant over 50 km from home. The model was tested in the Peninsula network (with additional work extending to the western network) and was able to predict the occupancy of each hospital and care level ( $R^2 = 0.85$ ), average distance from parents home within 2km and number of transfer to within 2%. The model also forecasted that centralisation would lead to reduced nurse requirements, assuming there is no requirement for neonatal cover at the birthing centre, but increased parent travel distance (average distance increased from 28km to 55km and number of parents >50km from the location of care increases from 15% to 60%). This then results in an increase in travel times, costs for parents and also decreases access to the baby unless accommodation is provided at the unit. Costs of nursing staff were dependent upon what percentage of the time BAPM guidelines were met (£4500 per infant if guidelines met 80% of the time and £5500 if guidelines met 95% of the time). However, there are limitations with this analysis as it based upon patient acuity (and not actual workload), it assumes the BAPM recommended skill mix (however, not all staff will be the same in respect to knowledge and skill) and it assumes a notional workload for a transitional care, which is poorly defined and a new category of care.

Taken together, these nine studies may provide some evidence that regionalization of neonatal services can increase the number of very preterm babies being delivered in high activity neonatal intensive care units, and this may confer to an increased survival rate. However, this evidence is observational in nature and thus at a risk of bias and should also be considered in the context of rapid advances in the field of neonatal medicine over the time period in which the studies are conducted.

#### 3.2.1.2.2 Primary studies on Workforce Configuration

Four studies examined the impact of staffing provision on neonatal outcomes. First, Hamilton et al. (2007) conducted a prospective study in 54 UK NICUs to examine if risk-adjusted mortality in 2636 VLBW or preterm infants (defined by the authors as gestation 31 weeks or less) is associated with levels of nursing provision in terms of total number of registered nurses per shift, nursing provision ratio per shift and specialist nursing provision ratio per shift. Hamilton et al. reported that 57% of shifts were understaffed and 65% of units had an average provision ratio of less than 1. In addition,



23.6% shifts were understaffed for specialist nurse provision. Understaffed shifts increased for night shifts. Interestingly, there was no significant difference in risk-adjusted mortality and nursing provision per shift, however, the risk of mortality was associated with low specialist nursing ratios (OR:0.52, 95%CI: 0.33-0.83). This study, although observational in nature, therefore suggests that increasing the ratio of specialist nurses to care for infants with intensive or high dependency care needs, may improve survival.

Secondly, the UK Neonatal Staffing Survey Group (2002) conducted a national census of 186 NICUs, which were stratified by activity (high, medium and low) and by high and low consultant and nursing provision. Complete data was available for 13334 infants and identified that high-volume NICUs cared for the sicker infant and had the highest crude mortality. However, after adjusting for risk there were no significant differences in mortality or cerebral damage between activity levels or staffing provision of units. However, nosocomial bacteraemia was less frequent in NICUs low consultant provision (OR: 0.65, CI: 0.43-0.98). Crucially, infants that were admitted when the unit was at 50% occupancy (and plausibly had higher staffing levels per baby) had about 50% lower odds of dying compared to infants admitted at maximum capacity.

Thirdly, in a non-UK study, Rogowski et al. (2013) conducted a retrospective cohort study to assess the impact of nurse understaffing on VLBW infants who received three or more days of NICU treatment in a unit subscribing to the Vermont Oxford Network, US in 2008 (n=5771) and 2009 (n=5630). It should be noted that the hospitals within the network had more teaching hospitals, larger units and more hospitals that had received recognition for nursing excellence than the US average. The authors reported that on average, 47% of all NICUs were understaffed in 2008 and 31% in 2009. A one standard deviation increase in the amount of a nurse per infant needed to meet guidelines was associated with a higher adjusted risk of infection for 2008 (adjusted OR: 1.39; 95% CI:1.19-1.62) and 2009 (adjusted OR: 1.40; 95% CI:1.19-1.65), suggesting that higher levels of nursing provision are associated with decreased risk of infection.

Finally, in a very recent article, Watson et al. (2016), estimated the effect of the provision of one-to-one nurse-to-patient ratio on mortality rates in 43 tertiary-level neonatal units in England between 2008 and 2012. The authors reported that the proportion of infants receiving one-to-one care reduced from 39.4% to 35.7% between 2008 and 2012. From the data, Watson et al. (2016) estimated that a 10% reduction in the proportion of intensive care days which one-to-one care was provided was associated with an increase in mortality rate of 0.6 deaths per 100 infants receiving intensive care per month (95% CI: -1.2-0.0). This study and the study by Rogowski et al. (2013) are limited as it can only identify the effect of a marginal increase in one-to-one nursing provision, nor does it tell us if increase in staffing would be advantageous during the whole admission or at specific points. Moreover, it does not consider what the impact of greater than one-to-one nursing provision might be.

Whilst these studies are observational and have limitations, few measured outcomes and are potentially at risk of bias, they have been identified in this review as the available evidence on staffing and do suggest that under-staffing and over-crowding are associated with poorer outcomes for infants requiring care. In addition, increasing specialist nursing provision warrants further exploration as it may be associated with improved outcomes.

### 3.3.2 Guidelines

#### 3.3.2.1 NICE

As noted the only included documents from NICE were the guideline on donor milk banks (NICE, 2010a) and the quality framework for neonatal specialist care (see table 3.1; NICE 2010a). First, donor milk banks may be used if the mother is unable to express sufficient milk or does not wish to express milk for a baby unable to feed at the breast. The guideline provides recommendations on the safe and effective operation of donor milk services, although no recommendations are made on service configuration. Information is provided on quality assurance, selecting and screening donors, handling milk, tracing and tracking (see NICE 2010b).

**Table 3.1 NICE Quality Standard on Neonatal Specialist Care: List of Statements**

Statement 1	In-utero and postnatal transfers for neonatal special, high-dependency, intensive and surgical care follow perinatal network guidelines and care pathways that are integrated with other maternity and newborn network guidelines and pathways.
Statement 2	Networks, commissioners and providers of specialist neonatal care undertake an annual needs assessment and ensure each network has adequate capacity.
Statement 3	Specialist neonatal services have a sufficient, skilled and competent multidisciplinary workforce.
Statement 4	Neonatal transfer services provide babies with safe and efficient transfers to and from specialist neonatal care.
Statement 5	Parents of babies receiving specialist neonatal care are encouraged and supported to be involved in planning and providing care for their baby, and regular communication with clinical staff occurs throughout the care pathway
Statement 6	Mothers of babies receiving specialist neonatal care are supported to start and continue breastfeeding, including being supported to express milk.
Statement 7	Babies receiving specialist neonatal care have their health and social care plans coordinated to help ensure a safe and effective transition from hospital to community care.
Statement 8	Providers of specialist neonatal services maintain accurate and complete data, and actively participate in national clinical audits and applicable research programmes.
Statement 9	Babies receiving specialist neonatal care have their health outcomes monitored.

The NICE quality standard is supported by Bliss, BAPM, RCPH, RCOG and the RCM. It is based upon three sources of information: Department of Health Toolkit for high quality neonatal services (NHS & Dept. of Health, 2009); BAPM Service standards for hospitals providing neonatal care (BAPM, 2010b); Royal College of Obstetricians and Gynaecologists Standards for maternity care: report of a working party (RCOG et al., 2008). However, it should be noted these are all consensus based documents as there was no relevant NICE guidance or NHS Evidence accredited sources available.

Nevertheless, the quality standard does provide some guidance from which key principles for care can be distilled. Specifically, it states that the “physical, psychological and social needs of babies and their families are at the heart of all care given” (NICE, 2010b, p.5) and an integrated approach to service provision is necessary for high quality care. In addition nine statements for the provision of neonatal care are provided and detailed in table 3.1.

#### 3.3.2.2 Department of Health

The Toolkit for High Quality Neonatal Services (NHS & Dept. of Health, 2009), was developed using evidence when possible or consensus of opinion. Based upon this eight principles for neonatal care

provision were stipulated along with markers for good practice. See table 3.2 for a brief summary or NHS & Dept. of Health (2009, p.39-60 for full details).

Principle	Description	Example Markers of Good Practice
1. Organisation of neonatal services	Neonatal care should be organised in a managed clinical network to ensure appropriate expert treatment	<ul style="list-style-type: none"> <li>• Agreed governance structure</li> <li>• Involvement from stakeholders</li> <li>• Encourage research activity</li> <li>• Monitoring of quality markers</li> </ul>
2. Staffing of neonatal services	An adequate and appropriate workforce with the leadership, skill mix and competencies to provide excellent care at the point of delivery	<ul style="list-style-type: none"> <li>• 70% of SCBU and 80% of HDU or NICU staff are registered</li> <li>• Minimum of 70% of registered nurses have a post-registration qualification in specialised neonatal care</li> <li>• Staff: Infant ratio for ICU is 1:1, for HDU is 1:2 and for SCBU is 1:4.</li> <li>• SCBU and HDU have 24hr consultant paediatrician availability</li> <li>• Intensive care units have 24hr neonatology consultant cover</li> </ul>
3. Care of the baby and family experience	Family-centred care is defined as a “philosophy of care that helps families whose baby is in hospital to cope with the stress, anxiety and altered parenting roles that accompany their baby’s condition. It puts the physical, psychological and social needs of both the baby and their family at the heart of all care given” (p. 46)	<ul style="list-style-type: none"> <li>• Parents have unrestricted access to the baby unless justified on an individual basis</li> <li>• Parents are encouraged and supported to participate in decision making, care provision and discharge planning</li> <li>• Every baby is treated with dignity and respect</li> <li>• Parents have the opportunity to meet with the consultant within 24hrs of admission</li> <li>• Breastfeeding is supported</li> <li>• Dedicated facilities (e.g. overnight accommodation) is available for parents</li> </ul>
4. Transfers	Service available at all times to provide safe and effective transfers and recognises family circumstances.	<ul style="list-style-type: none"> <li>• Network guidelines for <i>in utero</i> and <i>ex utero</i> transfers</li> <li>• Single point of phone contact for clinical advice and cot /maternal bed availability</li> <li>• Parents given opportunity to accompany baby and if not possible alternative arrangements are made</li> </ul>
5. Professional competence, education and training	Members of the MDT should have access to education and training to provide competence in delivering high quality care	<ul style="list-style-type: none"> <li>• All staff competent in neonatal resuscitation</li> <li>• Registered and non-registered nursing staff should take accredited training relevant to their role</li> </ul>

6. Surgical Services	Babies requiring surgical care should receive the same level of medical neonatal care	<ul style="list-style-type: none"> <li>• Where possible neonatal surgery services should be located on the same site as maternity and NICU services</li> <li>• Surgical services have processes for follow-up</li> </ul>
7. Clinical Governance	A network framework will monitor the quality of care provided, encourage excellence and improvement and ensure accountability and safety	<ul style="list-style-type: none"> <li>• Regular review of quality indicators</li> <li>• Annual network MDT meetings to monitor trends</li> <li>• Documented records of information provided to parents</li> <li>• Clear, accurate and retrievable records.</li> <li>• Participation in confidential enquiries where appropriate</li> </ul>
8. Data requirements	High quality data allows provision of accurate information to clinicians, researchers and families.	<ul style="list-style-type: none"> <li>• Dataset maintained to collate qualitative and quantitative data in relation to key performance indicators</li> <li>• Documented process for data validation</li> </ul>

The Health Building Note on neonatal services provides “best practice” guidance on the design and planning of healthcare facilities (Dept. of Health, 2013). In addition to specific and technical details about the configuration of neonatal units, this document provides guidance on how the neonatal unit can be designed around a family centred model of care. This includes rooming-in facilities, family rooms, self-catering facilities, bathrooms, and a play area for siblings to enable parents to visit, stay with and care for the baby. In addition day facilities should be provided for non-resident families and other visitors.

### 3.3.2.3 BAPM

As noted, the BAPM website search identified five relevant documents, however, it must be noted that much of this is based upon non-systematic reviews and consensus views. Nevertheless these documents may provide some practical guidance.

First, BAPM provide definitions of different categories of care as follows (BAPM, 2011b):

- Intensive Care. Care provided for babies who are the most unwell or unstable and have the greatest needs in relation to staff skills and staff to patient ratios. Includes aspects of care such as respiratory support, arterial lines, insulin infusion, chest drain and dialysis.
- High Dependency Care. Care provided for babies who require highly skilled staff but where the ratio of nurse to patient is less than intensive care. Includes aspects of care such as non-invasive respiratory support, parental nutrition, PICC line, urinary catheter or barrier nursing.
- Special Care. Care is provided for babies who require additional care delivered by the neonatal service but do not require either Intensive or High Dependency care. Includes aspects of care such oxygen via a nasal cannula, feeding by nasogastric, jejunal tube or gastrostomy, IV cannula or phototherapy.
- Transitional Care. Mother must be resident with her baby and providing care, but care can be delivered in a dedicated transitional unit or within a postnatal ward. It includes aspects of

care above that normally provided with support from a midwife/healthcare professional who does not require specialist neonatal training. This includes LBW infants, those requiring treatment such as antibiotics or stable infants requiring an opiate withdrawal programme.

These levels of care provide a useful definition, which can be utilised in this rapid review. The following recommendations for staffing levels in NICUs is also provided by BAPM in the 'Optimal Arrangements for Neonatal Intensive Care Units in the UK including guidance on their Medical staffing: A Framework for Practice' document, which provides the following recommendations (BAPM, 2014, p.2):

- Neonatal Intensive Care Units (NICUs) in the UK should admit at least 100 very low birth weight (VLBW) babies per year
- NICUs in the UK should undertake at least 2000 days of respiratory support per year
- All UK NICUs should comply to existing standards of nurse to baby ratios (1:1 NICU, 1:2 HDU, and 1:4 SCBU) and cot occupancy as well as those related to family and parent quality of experience
- Units with more than 7000 deliveries should augment their tier 1 medical support
- NICUs undertaking more than 2500 Intensive care (IC) days per annum should augment their tier 2 medical cover and provide two consultant led teams during normal hours
- Neonatal consultant staff should be available on site in all NICUs for at least 12 hours a day and for units undertaking more than 4000 intensive care days per annum\* consideration should be given to 24 hour consultant presence.

Further detail on staffing and also service configuration is also reported in the BAPM Service Standards for Hospitals Providing Neonatal Care (BAPM, 2010a). Specific to this review, there is guidance on the following: size of network (both in terms of population and geographical area); the role of the nurse (in terms of enhanced skills and advanced practitioner status); provision of facilities that care for both mother and babies (that allows the families to be resident if necessary); medical neonatal care for babies requiring surgical care; delivery room care for sick babies; arrangements for *in-utero* transfer if mother's health is not at risk and the baby may require high dependency or neonatal care; establishment of lead centres that lead on education, training, guideline development and audit; roles, competencies and qualifications for neonatal nurses (of all grades) and non-registered clinical staff; roles and grades of medical staff; staffing requirements for different levels of care; and standard for Allied Health Professionals (for further details see BAPM, 2010a)

In addition BAPM (BAPM, 2011a) also provides a framework for provision of neonatal support for Free-standing Midwifery Units (FMUs). It provides guidance on the following: governance; patient selection; patient information; management of a woman who wishes MLU delivery against professional advice; staff skill mix; setting environment and equipment; neonatal training for staff; neonatal resuscitation; emergency procedures and communication; and neonatal transfers. This framework, therefore provides general guidance that can be utilised in developing local, regional or network work guidelines (for further details see BAPM, 2011a).

Finally, BAPM have also produced guidelines on the design of neonatal units (Laing et al., 2004). These guidelines provide information on: position of unit (in terms of relation to the labour suite); number of cots; work flow patterns (i.e. access to labour suite, operating theatres, radiology, clinical support areas, family access, on call facilities, offices of senior clinical staff, mortuary); atmosphere (i.e. welcoming and comfortable for the infant and its family); details on provision of specific types of equipment; and requirements of numbers and location of HDU, ICU and SCBU cots (i.e. individual

rooms versus multiple bed rooms). The guidelines also provide information on how to provide a family friendly environment, specifically (Laing et al., 2004):

- Natural lighting in all clinical areas, quiet rooms and parents' bedrooms
- Translucent glass for windows facing onto internal corridors to maintain privacy and allow some natural daylight in
- A welcoming parents room that includes lockers, a children's play area and family education areas (e.g. guide to the NICU, leaflets on common conditions, information on help available)
- Parents' bedrooms in close proximity to the infant's cot. This particularly important for tertiary referral centres. It is recommended that the bedroom should be 2 sqm and include an en suite toilet and shower. The room should also have a double bed, couch, television and phone. Décor must be carefully chosen.
- Quiet rooms. It is recommended that a large NICU has two quiet rooms, which should have carefully thought out furniture. Facilities should be available for serving refreshments.

Whilst not based on systematic reviews, the BAPM documents identified are informed by expert opinion and available literature. They provide useful information on workforce configuration, staff roles and design features of neonatal units that can facilitate family centred care.

#### 3.3.2.4 RCN

Two guidelines relating to neonatal care provision and published by the RCN were identified. First, the Guidance for good practice on breastfeeding in children's wards and departments (RCN, 2013a), which is based upon a non-systematic literature review reports that Mothers of preterm infants should be supported to start and continue breastfeeding, including being supported to express milk. In addition, it also recommends that units provide equipment for expression and storage of breast milk. Secondly, the RCN standards for clinical professionals and service managers on defining staffing levels for children and young people's services (RCN, 2013b), uses the Department of Health Neonatal Toolkit's nurse: infant ratios detailed in 3.3.2.3. In addition, The RCN (2013a) guidance recommends that In NICUs and HDUs, 80% of nursing capacity should be registered nurses and in SCBUs 70% of nursing capacity should be registered nurses. It is also recommended (RCN, 2013a) that 70% of the registered nurses should hold a post-registration neonatal nursing qualification and unregistered staff should have undertaken training to a minimum of NVQ3 or foundation degree and work under the supervision of a registered nurse.

#### 3.3.2.5 BFI

The BFI standards were published by Unicef UK and developed as part of a consultation with clinicians, academics and policy makers and mothers (Unicef UK, 2012). These standards were developed in recognition of the importance of a positive parent/baby relationship in terms of promoting the well-being and development of babies. More specifically, an evidence review by BFI reported that long-term neurodevelopmental outcomes are improve in preterm infants who receive human breastmilk (Unicef UK, 2013). Moreover, infants receiving formula in a high-risk environment such as a NICU were at increased risk of infection, necrotising enterocolitis, delayed transition from parental to enteral feeding, delayed discharge home and reduced neurodevelopmental outcomes (Unicef UK, 2013) The standards outline how women should be supported to breastfeed in maternity services, neonatal units, health visiting services and children's centres/early years settings. Specific to neonatal units there are three standards, which can be met with the following approaches (Unicef UK, 2012):

1. Support parents to have a close and loving relationship with their baby:

- Providing parents unrestricted access to their baby unless individual restrictions can be justified in the baby's best interest.
  - Having a discussion with parents as soon as possible about the importance of touch, comfort and communication for their baby's health and development.
  - Actively encouraging parents to provide comfort and emotional support for their baby including prolonged skin contact, comforting touch and responsiveness to their baby's behavioural cues.
2. Enable babies to receive breastmilk and to breastfeed when possible:
- The mother's own breastmilk is always the first choice of feed for the baby.
  - Having a discussion as soon as appropriate with the mother regarding the importance of their breastmilk for their preterm or ill babies as soon as possible.
  - Mothers are enabled and given support to express breast milk as soon as possible after birth (ideally within two hours). This includes:
    - Support and education on hand expression, breast pump equipment and safe storage of milk.
    - Frequently expressing milk (especially in the first weeks after birth).
    - Stay close to the baby when expressing milk.
    - Access to effective breast pump equipment.
    - Access to further help with expressing if milk supplies are inadequate.
    - Use of breastmilk for mouth care if baby unable to tolerate oral feeds.
  - Within the unit there should be evidence of:
    - A suitable environment conducive to effective expression is created.
    - A formal review of expressing is undertaken a minimum of four times in the first two weeks to support optimum expressing and milk supply.
    - Appropriate interventions are implemented to overcome breastfeeding/expressing difficulties where necessary
  - Mothers should receive care that supports the transition to breastfeeding, including:
    - Being able to be close to their baby as often as possible so that they can respond to feeding cues.
    - Use of skin-to-skin contact to encourage instinctive feeding behaviour
    - Information about positioning for feeding and how to recognise effective feeding.
    - Additional support to help with breastfeeding/expressing challenges when needed.
  - Mothers are prepared to feed and care for their baby after discharge from hospital, including:
    - Having the opportunity to stay overnight/for extended periods to support development of the mother's confidence and modified responsive feeding.
    - Information about how to access support in the community.
    - There is no advertising for breastmilk substitutes, bottles, teats or dummies anywhere in the service or by any of the staff.
3. Value parents as partners in care:
- The unit makes being with their baby as comfortable as possible for parents (for example, by creating a welcoming atmosphere, putting comfortable chairs by the side of each cot, giving privacy when needed or providing facilities for parents to stay overnight).

- Staff enable parents to be fully involved in their baby's care.
- Every effort is made to ensure effective communication between the family and the health care team (including listening to parents' feelings, wishes and observations).

These standards reflect the importance of family centred care and the provision breastmilk for infants in neonatal units. They can therefore act as a guide for all neonatal units in Scotland to adhere to, in terms of enabling family-centred care and supporting mothers to provide breastmilk for their babies.

#### 4.0 Conclusion

Establishing a positive parent/baby relationship is crucial for promoting the well-being and development of infants requiring neonatal services. In order to achieve the best outcomes for such infants, the model of care therefore needs to be developed with this in mind. The aim of this rapid review was therefore to distil core principles and practice recommendations that could lead to effective, equitable, sustainable and acceptable care provision for infants requiring neonatal care and their families. The review identified 30 systematic reviews, which were broadly divided into the following categories: parents' views and experiences of neonatal care units (n=11); methods for improving family-centred care (n=10); service configuration (n=5), transitional/discharge care (n=3) and workforce configuration (n=1). In addition, thirteen primary studies not included in the systematic reviews and which examined service (n=9) and workforce configuration (n=4), were also identified and included in the review. Guidelines from British Association of Perinatal Medicine (BAPM) and the Department of Health, and a NICE quality framework were also identified as part of the review.

The evidence from the systematic reviews of parents views and experiences of neonatal care for their infant were generally judged to be of poor quality due to lack of critical appraisal conducted by the review authors. However, some key themes did recur across the reviews and these could be considered in the designing the optimal model of care for neonatal services which also take the families' needs into account. Specifically, we can stipulate that families need to have the opportunity to have as much contact with the baby as possible and as far as possible be involved in providing care including breastfeeding and kangaroo care and also decision-making processes. A family-centred model of care such as this, enables parents to take on a parental identify and provide a sense of normality, at a very stressful time. In order to facilitate this, staff need to be trained on aspects of family-centred care such as breastfeeding and kangaroo care. It is also essential that a positive relationship is built up with the health professionals looking after the infant, whereby, they are welcoming to parents (i.e. do not act as gatekeepers), provide plenty of opportunity for questions and help empower parents to look after their infant.

In terms of interventions/actions for improving family-centred a range of reviews of diverse interventions were identified. Two of these were high quality Cochrane reviews on the use of kangaroo care in stable infants which reported a wide range of benefits in terms of infant and mother outcomes. Another high quality Cochrane review examined cot-nursing versus incubator care on temperature control and weight gain in preterm infants and reported that there was no significant difference in temperature control and weight gain when a heated water filled mattress was used instead of an incubator. However, this was based on a small number of small studies and the authors urge caution in interpreting the results and urging more research in this area. Another Cochrane review on the use of audio recordings of consultations identified no studies, highlighting a gap in this area. Finally a well-conducted HTA review found strong evidence that short periods of



kangaroo care (up to 1hr) increased the duration of breastfeeding up to 1 month post discharge. There was also evidence that simultaneous pumping with an electric pump has advantages for the duration of breastfeeding in the first two weeks. Strong evidence was found for peer support delivered at home or in hospital. BFI accreditation of the maternity unit was also associated with an increase in number of infants receiving any breastmilk – new guidelines for BFI accreditation for neonatal units are now available and may be beneficial – evaluation is needed. In addition Benzie et al. (2013) reported that parenting programmes (educational interventions, psychosocial support and developmental interventions) helped to reduce maternal anxiety and depressive symptoms and had positive effects on self-efficacy and connectivity. However, there was considerable heterogeneity and there was no specific intervention that consistently conferred the most benefit.

Five systematic reviews examined configuration of services, specifically, regionalisation of care and neonatal transport. These reviews had a significant number of limitations in terms of included studies (e.g. date of publication, poor quality, lack of studies) so pertinent primary literature was sought instead. The primary studies also focused on the effect of regionalisation of neonatal care in terms of outcomes related to neonatal mortality and morbidity and also place of birth. It should be cautioned that these studies observational and potentially at risk of bias, but they were conducted in either UK or EU settings and may represent the best available evidence. Together, these studies suggest that regionalization of neonatal services can increase the number of very preterm infants and VLBW infants being delivered in high activity neonatal intensive care units, and this may result in a decreased mortality rate for the most vulnerable infants. However, whilst centralisation of intensive care services may provide the optimal outcomes for very preterm, VLBW and very sick infants a different model of service provision would potentially be more appropriate for preterm infants who are more mature (>32 weeks) or higher birth weight (>1500g) and otherwise stable. Any service configuration that requires babies to move a distance from their home should pro-actively consider how to support parents to remain in close contact with their infants and also facilitate a return to more localised care as soon as possible to ensure parental involvement can be optimised.

Only one review examining workforce configuration was identified and this reported that low nurse-patient ratio was associated with higher mortality. Whilst this review was of adequate quality, the included studies were of variable quality and caution is needed when interpreting their results. Due to the lack of systematic review level evidence, four additional primary studies were identified and included in the review. Again these studies have limitations, particularly as they are observational. However, they do suggest that under-staffing and over-crowding are associated with poorer outcomes for infants requiring care. In addition, one study specifically examined the effect of specialist nursing provision and provided evidence in support of increasing this particular form of provision. Addressing understaffing could potentially improve outcomes, it is recommended that an economic analysis is conducted to explore this further.

Finally only one systematic review, which included one study on early supported discharge was identified. Whilst this showed positive results, it highlights a dearth of evidence in this area and a need for further research to examine the safety, efficacy, acceptability, and resource implications of early supported discharge.

A small number of guidelines from the Department of Health, Royal College of Nursing (RCN) and BAPM, and the NICE quality framework were identified. These also highlight the potential importance of a family centred-approach to neonatal care and provide guidance on how to promote this. In addition they provide practical details relating to service and workforce configuration.

Finally, these results should be viewed in conjunction with the rapid reviews on improving interprofessional working and also the maternal critical care review, both of which highlighted the need for joined-up care. This applies to care the mother and the baby may individually receive from different professionals and/or services, but also to care that affects both the mother and the baby jointly. For instance, in providing support for breastfeeding in the neonatal unit or in the case of mothers who are unwell or have had a difficult birth. Moreover, in the case of multiple births care and attention must be given to ensure that these principles are adhered to so that parents are offered help to be in contact and provide breastmilk with all of their babies who may be receiving different levels of care (e.g. see Multiple Births Foundation, 2011). The mother and babies (and father) should therefore be considered as one unit and care should be delivered in a manner which recognises this.

#### 4.3 Strengths and limitations

This rapid review has several major strengths. First the focus on highly processed evidence in the form of Cochrane reviews and guidelines, ensures that not only the best available evidence is identified but also that the evidence has been considered and reviewed by researchers, health care practitioners and lay users. This rapid review is therefore able to build upon consensus that has already been developed regarding the quality, acceptability and transferability of the research and the interventions. Secondly, when systematic review evidence was not available, the best available (in terms of quality and relevance to Scotland) studies were identified in an efficient manner through reference lists of the systematic reviews, the database search and expert consultation. Thirdly, the development of the rapid review (i.e. review questions, search strategy) was based upon a pre-existing framework (the Framework for quality maternal and newborn care, Renfrew et al., 2014) which itself is based upon the best available evidence in maternity care in the form of Cochrane reviews and a meta-synthesis of women's views and experiences. Finally, the review sought to identify studies on women and their family's views and experiences as well as studies which measured outcomes of interventions. This will help guide not only what is the most effective approach (in terms of outcomes) but also what is the most acceptable approach to families.

However, due to the rapid nature of this piece of work and the vast nature of the topic area, there are a number of limitations to this review that must be considered. First, the search retrieval methods for the primary studies were a limitation as well as a strength of this rapid review. The database search did not explicitly set out to identify primary studies (although some were still retrieved by the search) and primary studies were mainly identified through expert consultation and reference lists. It is therefore feasible that potentially relevant studies will not have been captured by this review. Secondly, the reviews of qualitative studies on women's views and experiences were generally of low quality (although the studies themselves were of mixed quality). Finally, the majority of primary studies on service configuration were observational studies. Although they were generally of an adequate quality for an observational study, the lack of experimental design increases the risk of bias. Caution is therefore urged in the interpretation of results.

## Appendix 1. Search Strategies

### MEDLINE

Medline searched using the Ovid platform on 09/3/2016.

Search terms detailed below. Systematic review filter is the MEDLINE systematic review search strategy developed by the NHS Centre for Reviews and Dissemination at the University of York.

No. of records = 1213

- 1 (perinat\* or neonat\* or newborn or new born or infant\* or baby or babies).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 2 exp Infant, Newborn/
- 3 Infant, Premature/
- 4 Infant, Extremely Premature/
- 5 (preterm or prematur\*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 6 exp Infant, Low Birth Weight/
- 7 low birth weight.mp.
- 8 exp Infant, Very Low Birth Weight/
- 9 Intensive Care Units, Neonatal/
- 10 Intensive Care, Neonatal/
- 11 Infant, Premature, Diseases/
- 12 neonat\* intensive care.mp.
- 13 NICU.mp.
- 14 neonat\* unit.mp.
- 15 Neonatal Nursing/
- 16 neonat\* care.mp.
- 17 special care baby unit.mp.
- 18 SCBU.mp.
- 19 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 18
- 20 regionalization.mp.
- 21 regionalisation.mp.

- 22 (centralization or centralisation).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 23 "Delivery of Health Care"/og, sd, ut [Organization & Administration, Supply & Distribution, Utilization]
- 24 health care organization.mp.
- 25 health care organisation.mp.
- 26 health care distribution.mp.
- 27 level 3 neonatal.mp.
- 28 level 2 neonatal.mp.
- 29 level 1 neonatal.mp.
- 30 27 or 28 or 29
- 31 19 or 30
- 32 hospital activity.mp.
- 33 hospital expertise.mp.
- 34 neonatal network.mp.
- 35 clinical network.mp.
- 36 20 or 21 or 22 or 23 or 24 or 25 or 26 or 32 or 33 or 34 or 35
- 37 31 and 36
- 38 neonatal transfer.mp.
- 39 Patient Transfer/ and neonat\*.mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 40 37 or 38 or 39
- 41 model of care.mp.
- 42 service configuration.mp.
- 43 workforce configuration.mp.
- 44 "Personnel Staffing and Scheduling"/ or "Health Services Needs and Demand"/ or Health Planning/ or Workload/ or Rural Health Services/
- 45 supported discharge.mp.
- 46 early discharge.mp.
- 47 step down care.mp.
- 48 Nurse-Patient Relations/ or Patient-Centered Care/ or Physician-Patient Relations/

THIRD DRAFT

- 49 Family cent?red care.mp.
- 50 patient cent?red care.mp.
- 51 (family adj3 focus).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 52 (child adj3 focus).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 53 ('partnership in care' or 'partners in care' or 'involvement in care' or 'share care').mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 54 ('care by parent' or 'care-by-parent').mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 55 ((family or parent) adj3 (care or participat\* or involv\* or decision or share or collaborat\* or communicat\*)).mp. [mp=title, abstract, original title, name of substance word, subject heading word, keyword heading word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier]
- 56 40 or 41 or 42 or 43 or 44 or 45 or 46 or 47 or 48 or 49 or 50 or 51 or 52 or 53 or 54 or 55
- 57 meta-analysis/
- 58 exp review literature/
- 59 (meta-analy\$ or meta analy\$ or metaanaly\$).tw.
- 60 meta analysis.pt.
- 61 review academic.pt.
- 62 review literature.pt.
- 63 letter.pt.
- 64 review of reported cases.pt.
- 65 historical article.pt.
- 66 review multicase.pt.
- 67 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65 or 66
- 68 31 and 56
- 69 67 and 68

THIRD DRAFT

CINAHL

CINAHL searched using the EBSCO platform on 09/03/2016.

Search terms detailed below. Systematic review filter applied was reported by Wong et al. (2006).  
Search limited to 2000 - current

No. of records = 592.

- S57 S49 AND S55
- S56 S49 AND S55
- S55 S50 OR S51 OR S52 OR S53 OR S54
- S54 PT review
- S53 PT systematic review
- S52 (MH "Systematic Review")
- S51 systematic review
- S50 meta-analysis
- S49 S20 AND S48
- S48 S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32 OR S33 OR S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47
- S47 delivery of health care
- S46 health care organisation
- S45 "health care organization"
- S44 centralization OR centralisation
- S43 regionalisation
- S42 "regionalization"
- S41 hospital activity OR hospital expertise
- S40 "clinical network AND neonat\*"
- S39 "neonatal network"
- S38 (family or parent) N3 (care or participat\* or involv\* or decision or share or collaborat\* or communicat\*)
- S37 'care by parent' or 'care-by-parent'
- S36 'partnership in care' or 'partners in care' or 'involvement in care' or 'share care'
- S35 family N3 focus
- S34 patient cent?red care

THIRD DRAFT

- S33 (MH "Patient Centered Care") AND neonat\*
- S32 Family centered care
- S31 (MH "Family Centered Care") OR (MH "Professional-Family Relations")
- S30 (MH "Nurse-Patient Relations") OR (MH "Physician-Patient Relations") OR (MH "Nurse-Patient Ratio") OR (MH "Patient-Family Relations")
- S29 step down care
- S28 early discharge
- S27 (MH "Early Patient Discharge") AND neonat\*
- S26 "supported discharge"
- S25 (MH "Health Services Needs and Demand")
- S24 (MH "Health Facility Planning")
- S23 (MH "Workforce") OR "workforce"
- S22 (service OR workforce) AND configuration
- S21 "model of care"
- S20 S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19
- S19 "neonatal transfer"
- S18 level 3 neonatal
- S17 "level 2 neonatal"
- S16 level 1 neonatal
- S15 SCBU
- S14 "special care baby unit"
- S13 neonat\* care
- S12 "neonatal unit"
- S11 NICU
- S10 neonat\* intensive care
- S9 (MH "Neonatal Nursing") OR (MH "Neonatal Intensive Care Nursing")
- S8 (MH "Intensive Care Units, Neonatal") OR (MH "Neonatal Intensive Care Nursing") OR (MH "Intensive Care, Neonatal")
- S7 low birth weight
- S6 (MH "Infant, Very Low Birth Weight") OR (MH "Infant, Low Birth Weight")
- S5 preterm or prematur\*

THIRD DRAFT

- S4 (MH "Infant, Premature, Diseases")
- S3 (MH "Infant, Premature")
- S2 (MH "Infant")
- S1 perinat\* or neonat\* or newborn or new born or infant

HMIC

HMIC searched using the Ovid platform on 09/3/2016

Note systematic review filter resulted in no records being identified so this was removed.

No. of records = 117

- 1 (perinat\* or neonat\* or newborn or new born or infant\* or baby or babies).mp. [mp=title, other title, abstract, heading words]
- 2 exp Neonates/
- 3 (preterm or premature).mp. [mp=title, other title, abstract, heading words]
- 4 exp Premature babies/
- 5 exp Premature baby units/
- 6 preterm.mp.
- 7 exp Low birth weight/
- 8 low birth weight.mp.
- 9 exp Neonatal care/
- 10 exp Neonatal units/
- 11 exp Neonatal intensive care/
- 12 (neonatal intensive care or neonatal unit or neonatal care or NICU).mp. [mp=title, other title, abstract, heading words]
- 13 exp Special care baby units/
- 14 (special care baby unit or SCBU).mp. [mp=title, other title, abstract, heading words]
- 15 exp Neonatal nursing/
- 16 neonatal transfer.mp.
- 17 exp patient transfer/ and neonat\*.mp. [mp=title, other title, abstract, heading words]
- 18 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17
- 19 model of care.mp.
- 20 service configuration.mp.



THIRD DRAFT

- 21 exp Workforce/  
22 workforce configuration.mp. [mp=title, other title, abstract, heading words]  
23 exp Staffing levels/ or exp Staffing/  
24 exp Health planning/  
25 exp Rural health services/  
26 exp Patient early discharge/  
27 early discharge.mp. [mp=title, other title, abstract, heading words]  
28 step down care.mp. [mp=title, other title, abstract, heading words]  
29 supported discharge.mp.  
30 exp Patient nurse relations/  
31 exp patient centred care/  
32 exp Patient medical staff communication/  
33 Family centred care.mp.  
34 patient centred care.mp.  
35 (family adj3 focus).mp. [mp=title, other title, abstract, heading words]  
36 (child adj3 focus).mp. [mp=title, other title, abstract, heading words]  
37 ('partnership in care' or 'partners in care' or 'involvement in care' or 'share care').mp.  
[mp=title, other title, abstract, heading words]  
38 ('care by parent' or 'care-by-parent').mp. [mp=title, other title, abstract, heading words]  
39 ((family or parent) adj3 (care or participat\* or involv\* or decision or share or collaborat\* or  
communicat\*)).mp. [mp=title, other title, abstract, heading words]  
40 regionalisation or regionalization  
41 centralisation or centralization  
42 health care organization  
43 health organization  
44 neonatal network  
45 clinical network AND neonatal  
46 hospital activity or hospital expertise  
47 19 or 20 or 21 or 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 or 38 or 39 or 40 or 41 or 42 or 43 or 44 or 45 or 46  
48 18 and 47  
49 limit 48 to yr="2000 -Current"

THIRD DRAFT

MIDIRS

Medline searched using the Ovid platform on 09/03/2016.

No. of records = 18

- 1 (perinat\* or neonat\* or newborn or new born or infant\* or baby or babies).mp.  
[mp=abstract, heading word, title]
- 2 (preterm or prematur\*).mp. [mp=abstract, heading word, title]
- 3 low birth weight.mp.
- 4 neonat\* intensive care.mp.
- 5 NICU.mp.
- 6 neonat\* unit.mp.
- 7 neonat\* care.mp.
- 8 special baby care unit.mp.
- 9 SCBU.mp.
- 10 regionalization.mp.
- 11 regionalisation.mp.
- 12 (centralization or centralisation).mp. [mp=abstract, heading word, title]
- 13 health care organization.mp.
- 14 health care organisation.mp.
- 15 level 3 neonatal.mp.
- 16 level 2 neonatal.mp.
- 17 level 1 neonatal.mp.
- 18 15 or 16 or 17
- 19 hospital activity.mp.
- 20 hospital expertise.mp.
- 21 neonatal network.mp.
- 22 clinical network.mp.
- 23 neonatal transfer.mp.
- 24 model of care.mp.
- 25 service configuration.mp.
- 26 workforce configuration.mp.
- 27 ["Personnel Staffing and Scheduling"/ or "Health Services Needs and Demand"/ or Health Planning/ or Workload/ or Rural Health Services/]

THIRD DRAFT

- 28 supported discharge.mp.
- 29 early discharge.mp.
- 30 step down care.mp.
- 31 Family cent?red care.mp.
- 32 patient cent?red care.mp.
- 33 (family adj3 focus).mp. [mp=abstract, heading word, title]
- 34 (child adj3 focus).mp. [mp=abstract, heading word, title]
- 35 ('partnership in care' or 'partners in care' or 'involvement in care' or 'share care').mp.  
[mp=abstract, heading word, title]
- 36 ('care by parent' or 'care-by-parent').mp. [mp=abstract, heading word, title]
- 37 ((family or parent) adj3 (care or participat\* or involv\* or decision or share or collaborat\* or  
communicat\*)).mp. [mp=abstract, heading word, title]
- 48 Neonate.de.
- 49 newborn.de.
- 50 (Infant - newborn or Infant or Infant - premature).de.
- 51 premature.de.
- 52 low birth weight.de.
- 53 Infant - low birth weight.de.
- 54 Neonatal intensive care.de.
- 55 (Intensive care - neonatal or Intensive care units - neonatal).de.
- 56 1 or 2 or 3 or 4 or 5 or 6 or 7 or 8 or 9 or 15 or 16 or 17 or 48 or 49 or 50 or 51 or 52 or 53 or  
54 or 55
- 57 Staffing.de.
- 58 Workforce.de.
- 59 "Personnel staffing and scheduling".de.
- 60 Family-centred care.de.
- 61 Professional-patient relations.de.
- 62 Patient-centred care.de.
- 63 Baby Friendly Hospital Initiative.de.
- 64 Decision making.de. and neonat\*.mp. [mp=abstract, heading word, title]
- 65 "Models of care".de.

THIRD DRAFT

66 10 or 11 or 12 or 13 or 14 or 15 or 16 or 17 or 19 or 20 or 21 or 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 or 57 or 58 or 59 or 60 or 61 or 62 or 63 or 64 or 65

67 56 and 66

68 Meta-analysis.de.

69 Systematic reviews.de.

70 systematic review.m\_titl.

71 meta-analysis.m\_titl.

72 evidence review.mp. [mp=abstract, heading word, title]

73 literature review.m\_titl.

74 68 or 69 or 70 or 71 or 72 or 73

75 67 and 74

## Appendix 2. Detailed study selection tables.

Table A2.1 NICE Guideline Search.

<b>Guideline</b>	<b>Details</b>	<b>Relevant to rapid review</b>
Guideline CG93. Donor milk banks: service operation	Examine evidence relating to planning donor milk services including for neonatal units.	Yes
Guideline CG98. Jaundice in newborn babies under 28 days.	Examines evidence on investigation and clinical management of jaundice. No evidence on care setting.	No.
Guideline PH11. Maternal and Child Nutrition.	Examines evidence on maternal and child nutrition from pre-conception to age 5 years. Does not specifically consider nutrition in neonatal care settings.	No
Guideline CG37. Postnatal care up to 8 weeks after birth.	Examines evidence on postnatal care. Focused on routine postnatal care so does not include neonatal care settings	No
Guideline NG4. Safe midwifery staffing for maternity settings.	Examines evidence on staffing of maternity settings. Neonatal unit admission is considered only in terms of being an outcome.	No
Quality Standard QS4. Neonatal Specialist Care.	Quality standards for the provision on neonatal care. It is based on consensus documentation from DoH Toolkit for high quality neonatal services, BAPM service standard for neonatal care and RCOG standards for maternity care as no relevant NICE guideline or NHS evidence accredited sources.	Yes

Table A2.2 Cochrane Pregnancy and Childbirth Group Search.

<b>Title</b>	<b>Exclude/ Include</b>	<b>Reason</b>
Audio recordings of consultations with doctors for parents of critically sick babies	Include	
Cot-nursing versus incubator care for preterm infants	Include	
Developmental care for promoting development and preventing morbidity in preterm infants	Exclude	Not focused on family centred care, or neonatal care configuration
Kangaroo mother care to reduce morbidity and mortality in low birthweight infants	Include	
Skin-to-skin (Kangaroo Care) with newborns cuts down procedural pain	Include	

Specialist teams for neonatal transport to neonatal intensive care units for prevention of morbidity and mortality	Include	
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Table A2.3 BAPM Search

<b>Guideline</b>	<b>Details</b>	<b>Relevant to rapid review</b>
Newborn Early Warning Trigger and Track (NEWTT) A Framework for practice.	Describes the development of a track and trigger system for newborns. In addition to identify babies at risk of deterioration and standardising monitoring, the system also aims to reduce admissions to NNUs. It is based upon a non-systematic literature review and consensus opinion.	No
Optimal Arrangements for Neonatal Intensive Care Units in the UK including guidance on their Medical Staffing A Framework for Practice	Provides guidance on optimal size and activity levels of NICUs in UK. Is based upon a non-systematic literature review and consensus opinion.	Yes
Practical guidance for the management of palliative care on neonatal units. Developed by RCPH.	Systematic review and when evidence not available consensus statements on provision of palliative care.	No
Categories of care	Details levels of neonatal care and examples of what care provided in each setting (intensive care, high dependency, special care, transitional care)	Yes for definitional purposes
Neonatal Support for Stand Alone Midwifery Led Units (MLUs) A Framework for Practice	Non-systematic literature review (plus possible expert opinion) on how to provide neonatal support for standalone midwife led units. Has some information on transport.	Yes, in terms of transport arrangements
Service Standards for Hospitals Providing Neonatal Care	Standards document for workforce configuration in neonatal units. Does not appear to be based on an evidence search.	Yes
The Management of Babies born Extremely Preterm at less than 26 weeks of gestation A Framework for Clinical Practice at the time of Birth	Non-systematic review on commencement of resuscitation based on gestational age.	No. Not focused on care model or configuration.

Management of acute in-utero transfers: a framework for practice	Details indications and contraindications for in-utero transfer. No detail on neonatal unit care model or configuration.	No
Classification of health status at 2 years as a perinatal outcome	Described develop of tool and not actual data.	No
Early care of the newborn infant. Statement on current level of evidence	Non-systematic literature review and consensus views on technical aspects of care (e.g. monitoring, use of drugs) but no detail on models or configuration of care.	No
Withholding or Withdrawing Life Sustaining Treatment in Children. RCPH document.	Document aims to provide practical help in making decisions on life sustaining treatment in children generally. No detail on models or configuration of care.	No
Designing a Neonatal Unit Report for the British Association of Perinatal Medicine	Provides information on the design of a neonatal unit does not seem to have an evidence base	Yes
UK Neonatal Staffing Study. Study funded by NHS R&D executive, mother and child health programme.	Census on neonatal care units and prospective cohort study to assess whether risk-adjusted mortality and morbidity outcomes of UK neonatal intensive care are related to organisational characteristics	No. Data collected between 1997 and 2000 so out of date.
National census of availability of neonatal intensive care. Study by Parmanum et al.	Census to determine whether availability of neonatal intensive care cots is a problem in any or all parts of the United Kingdom.	No. Study conducted <2000 so out of date.

Table A2.3 RCPH Guideline Search.

<b>Guideline</b>	<b>Details</b>	<b>Relevant to rapid review</b>
Breastfeeding: Position Statement	Statement encouraging mothers to breastfeed.	No
Children's and Maternity Services in 2009: Working Time Solutions	Evaluates impact of working time directive through survey of obstetrics and gynaecology and paediatrics.	No
Future of Paediatric Pathology Services - Fetal, Perinatal and Paediatric Pathology: A Critical Future	Report of a working group set up to review paediatric pathology	No
National Neonatal Audit Programme (NNAP) Annual Report 2011	Assesses whether babies admitted to neonatal units in England are receiving consistent care and to identify areas for	No

	improvement. Asks some potentially relevant questions on: consultation with parents, whether babies treated in own network or not, receiving mother's milk.	
National Neonatal Audit Programme (NNAP) Annual Report 2012	Assesses whether babies admitted to neonatal units in England and Wales are receiving consistent care and to identify areas for improvement. Asks some potentially relevant questions on: proportion of babies receiving transitional care, consultation with parents, whether babies treated in own network or not, receiving mother's milk.	No
National Neonatal Audit Programme (NNAP) Annual Report 2013	Assesses whether babies admitted to neonatal units in England and Wales are receiving consistent care and to identify areas for improvement. Asks some potentially relevant questions on: consultation with parents, whether babies treated in own network or not, receiving mother's milk.	No
Palate Examination: Identification of Cleft Palate in the Newborn	Recommendations for cleft palate examination	No
Palate Examination: Identification of Cleft Palate in the Newborn - A Guide for Parents and Carers	Guide for parents on cleft palate examination.	No
Rota Compliance and Vacancies Survey: December	Presents results of EWTR compliance survey and rota gaps/vacancies in England, Scotland, Wales and NI in 2012.	No
Sudden Unexpected Death in Infancy: A Multi-agency Protocol for Care and Investigation	Protocol for the investigation and care of families after the sudden unexpected death of an infant or young child	No
UK-WHO Growth Chart 0-4 years (boys)	Growth charts including for pre-term infants (32-36 weeks)	No
UK-WHO Growth Chart 0-4 years (girls)	Growth charts including for pre-term infants (32-36 weeks)	No
UK-WHO Height and Weight Chart 4-20 years for PCHR (boys)	Growth charts	No
UK-WHO Height and Weight Chart 4-20 years for PCHR (girls)	Growth charts	No
UK-WHO Growth Chart 0-4 years (boys)	Growth charts including for pre-term infants (32-36 weeks)	No
UK-WHO Growth Chart 0-4 years (girls)	Growth charts including for pre-term infants (32-36 weeks)	No
UK-WHO Growth Chart Childhood and Puberty Close Monitoring (CPCM) 2-20 years (boys)	Growth Chart	No



UK–WHO Growth Chart Childhood and Puberty Close Monitoring (CPCM) 2–20 years (girls)	Growth Chart	No
UK–WHO Neonatal and Infant Close Monitoring Growth Chart 23 weeks gestation to 2 years corrected age (boys)	Growth chart for very preterm infants	No
UK–WHO Neonatal and Infant Close Monitoring Growth Chart 23 weeks gestation to 2 years corrected age (girls)	Growth chart very preterm infant	No
RCPCH Medical Workforce Census 2013: 4 Focus on Tertiary Services	Neonatal subsection of 2013 paediatric workforce census.	No
The Diagnosis of Death by Neurological Criteria in Infants Less Than Two Months Old	Details the DNC in infants from 37 weeks gestation to 2 months post term	No
Reducing Mother to Child Transmission of HIV Infection in the United Kingdom: Update Report of an Intercollegiate Working Party	Update of the first intercollegiate report in 1998, which details progress to improve the uptake of HIV testing in antenatal clinics	No

Table A2.4 RCN Publication Search.

<b>Publication</b>	<b>Details</b>	<b>Relevant to rapid review</b>
Breastfeeding in children's wards and departments: Guidance for Good Practice	Good Practice Guidance on breastfeeding including in neonatal care settings. Provides some references but not a systematic review.	Yes (N.B. guidance only)
Formula feeds: RCN guidance for nurses caring for infants and mothers	Information booklet for parents who use formula feeding. No specific detail on infants in neonatal care.	No
Caring for children with fever	Good Practice Guidance on managing children with fever. No focused on neonatal care provision	No
Standards for assessing, measuring and monitoring vital signs in infants, children and young people	Information on vital sign assessment. Not specific to infants in neonatal care	No
Standards for the weighing of infants, children and young people in the acute health care setting	RCN guidance on weighing. Not specific to infants in neonatal care.	No
Defining staffing levels for children's and young people's services: RCN standards for clinical professionals and service managers	RCN standards for staffing levels. Includes guidance on number of registered and unregistered nursing staff working in different levels of neonatal care	Yes

## Appendix 3.1 Parents' views and experiences data extraction tables

<b>Study Details</b>	2559.
Author/year	Aggaard and Hall. 2008
Review theme	Parental Experience.
Objectives	To identify and synthesise recent nursing qualitative research on mothers' experiences of having a preterm infant in the NICU which can inform development of family-centred care
Participants (characteristics/number)	Mothers' (n=159) with either preterm and/or critically ill infants receiving neonatal care
Setting/Context	NICU
Description of Interventions/ phenomena of interest	Mothers' experiences of having a preterm and/or critically ill infant receiving neonatal care
<b>Search Details</b>	
Sources	PubMed, CINAHL, WOS and PsycINFO. Searching reference lists
Range (years) of included studies	2000-2005
No. of studies	14
Types of studies included	Qualitative including one ethnography. Used a range of analytical approaches including discourse, phenomenology, grounded theory and descriptive
Country of origin of included studies	USA, UK, Sweden, Australia, Denmark (even spread)
<b>Appraisal</b>	
Appraisal instruments used	Not stated (?if used)
Appraisal rating	Not stated
<b>Analysis</b>	
Method of analysis	Noblit and Hare's meta-ethnographic approach
Outcome assessed	N/A
Results/findings	<p>The following themes were identified:</p> <ul style="list-style-type: none"> <li>• Mother-baby relationship: from their baby to my baby. Mother fear attachment and seeing the baby elicits feelings of relief, alienation, fear and worry. Not getting to know the baby is upsetting and the mother may feel she needs to ask permission to care for her infant. Mother is vigilant to changes in the infant's condition.</li> <li>• Maternal Development: A Striving to be a Real Normal Mother. Mother not prepared and development of maternal identity is delayed. May feel out of control, have shattered expectations and unable to celebrate the baby's birth. Alarms and machines can be distressing but this is helped by kangaroo care which also calms the baby. Separation from the baby leads to feelings of guilt and abandonment. Strong urge to claim the role of a mother but constraints and constant supervision contribute to feelings of not being a "normal mother". But being able to make choices about care, being part of the team and acts of caring contributed to a</li> </ul>

	<p>women’s sense of being a mother. Developmental process from being an outsider to becoming an engaged parent.</p> <ul style="list-style-type: none"> <li>• A turbulent neonatal environment: from foreground to background. The NICU is overwhelming to the mother in terms of noise, business and technology. As the mother becomes more comfortable in the unit, she might pay more attention to the baby.</li> <li>• Maternal caregiving and role reclaiming strategies: silent vigilance to advocacy. Caregiving is a developmental process from passive to active including include touching, soothing, and holding and subsequent physical care in the form of feeding, bathing, positioning, and changing. Some mothers fear voicing questions, concerns, wishes in case that makes her a difficult mother. Use strategies to protect the infant such as negotiating with HPs, use of institutional knowledge to challenge the institution’s authority, seeking a higher authority, building supportive relationships with other mothers and getting support from spouses, family and friends. Breastfeeding can help them feel like they are connecting and bonding.</li> <li>• Mother-Nurse Relationship. From Continuously Answering Questions Through Chatting to Sharing of Knowledge. Nurses are “gatekeepers” who mediate the relationship between parents and infants. Facilitative nursing actions include being kind, helpful, supportive, answering questions, reassuring and helping the mother get to know her child. Inhibitive nursing actions include being ignorant and not respecting the infant’s needs. Established relationships make asking questions easier. Lack of continuity of care (e.g. through frequent staff changes) impedes on the formation of a partnership with the nurses. The mother-nurse relationship is facilitated through chatting which allows the nurse share expertise/knowledge in a manner that makes the mother feel involved. With growing competence the mother may know her baby better than the staff but may perceive that the staff are not listening to her expertise.</li> </ul>
Significance/direction	N/A
<b>Comments</b>	Low quality review - no critical appraisal.

<b>Study Details</b>	1831.
Author/year	Alves et al. 2013.
Review theme	Parental Experience.
Objectives	To synthesise what is known about the parents’ views on factors that help or hinder breast milk supply during their infants’ hospitalisation in neonatal intensive care units (NICU).
Participants (characteristics/number)	Parents with a child who required NICU admission. Generally, single mothers, those who were not able to speak the native language and those whose babies had congenital malformations or were very close to death were excluded. 299 mothers and 9 mother-father pairs.
Setting/Context	Either during the NICU admission or post-discharge from hospital

Description of Interventions/ phenomena of interest	Parents' views on barriers/facilitators to breastfeeding during a NICU admission.
<b>Search Details</b>	
Sources	PubMed, WOS, PsycINFO, SciELO
Range (years) of included studies	1994-2011
No. of studies	7
Types of studies included	Qualitative (n=5) and mixed-methods (n=2). Most commonly semi-structured interviews.
Country of origin of included studies	Sweden, USA and England (and two did not provide information)
<b>Appraisal</b>	
Appraisal instruments used	None detailed
Appraisal rating	None detailed
<b>Analysis</b>	
Method of analysis	Content and thematic analysis (frequency of each theme was coded). Those reported >3 times are detailed in the results/findings
Outcome assessed	N/A
Results/findings	<p>Facilitators:</p> <ul style="list-style-type: none"> <li>• Contribution to infant's growth and wellbeing</li> <li>• Sense of normality</li> <li>• Opportunity to connect with the infant</li> <li>• Learning of techniques</li> <li>• Knowledge of infant's and women's bodies and behaviours</li> <li>• Positive reinforcement and feedback from staff</li> <li>• Provision of accurate information from staff</li> <li>• Confidence in staff</li> <li>• Peer counsellors</li> <li>• Sterile supplies</li> <li>• Perception of the NICU as comfortable</li> </ul> <p>Barriers:</p> <ul style="list-style-type: none"> <li>• Difficulties with pumping</li> <li>• Worries about adequacy of milk supply</li> <li>• Stressful nature of the NICU</li> <li>• Lack of privacy</li> <li>• Structured feeding routine</li> <li>• Lack of role models and/or social support, isolation and competing time demands</li> </ul>
Significance/direction	
<b>Comments</b>	Low quality review - no critical appraisal.

<b>Study Details</b>	792
Author/year	Butt et al. 2012
Review theme	Parental Experience

Objectives	To synthesize findings from the published empirical literature on parent satisfaction with care provided in the neonatal intensive care unit (NICU).
Participants (characteristics/number)	Parents (primarily mothers) and neonatal staff in two studies. Quantitative: parents (n=1733), staff (n=141). Qualitative: parents (n=26). Mixed methods: parents (n=148), staff (n=81)
Setting/Context	Infant in NICU (level II or III), or had been discharged from NICU
Description of Interventions/ phenomena of interest	To understand what parents' identify as important to satisfaction in a NICU setting which may provide insight into the weaknesses in the caregiving environment that may not be apparent or viewed as unimportant to caregivers.
<b>Search Details</b>	
Sources	CINAHL, Medline, Embase, PsycInfo, Sociological Abstracts, the Cochrane Library, and the Campbell Library. The reference lists of all studies were reviewed and the personal files of the authors were also searched for relevant studies.
Range (years) of included studies	1990-2012
No. of studies	12
Types of studies included	Quantitative descriptive (n=9), qualitative descriptive (n=2), mixed methods (n=1)
Country of origin of included studies	US, Canada, Australia, The Netherlands, South Africa and Israel (mainly US).
<b>Appraisal</b>	
Appraisal instruments used	No formal appraisal tool used. Studies were critiqued by comparing the study to the general principles of research rigor for the type of study design reported. Limitations of each study is presented in a table.
Appraisal rating	Considerable number of limitations identified including lack (or limited) reliability and validity of questionnaires, low response rates, selection bias, limited transferability and recall bias.
<b>Analysis</b>	
Method of analysis	Whittemore and Knaf's methodology for integrative reviews
Outcome assessed	Parent satisfaction
Results/findings	<ul style="list-style-type: none"> <li>• Parents degree of satisfaction with care. Quantitative sats showed that satisfaction varied between settings but generally parents reported a moderately high to high degree of overall satisfaction with care. Qualitative data identified issues with lack of communication with care providers and inconsistencies in practice between neonatal nurses (resulting in difficulties in knowing what to do in terms of care provision).</li> <li>• Correlates of patient satisfaction with NICU care. Little consensus on which parent or child demographic variables were correlated with satisfaction</li> <li>• Elements of care parents find important. Nurse-patient relationship influential on parents' satisfaction. Communication (in terms of information exchange), caregiving, being able to spend time with the child and perception of staff competence and ability anticipate child's needs were identified as important in developing satisfaction.</li> </ul>

	<ul style="list-style-type: none"> <li>Discrepancies between parent expectation and actual ratings of care. Despite generally high levels of satisfaction, the level of care does not often meet the expectations of parents.</li> </ul>
Significance/direction	N/A
<b>Comments</b>	Adequate quality review but included studies at high risk of bias

<b>Study Details</b>	1094
Author/year	Cleveland 2008
Review theme	Parental Experience
Objectives	A systematic review of the literature was conducted to answer the following 2 questions: (a) What are the needs of parents who have infants in the neonatal intensive care unit? (b) What behaviors support parents with an infant in the neonatal intensive care unit?
Participants (characteristics/number)	Parents (predominantly mothers)
Setting/Context	NICU (level II and III) care for infants who are either preterm, sick and/or LBW
Description of Interventions/ phenomena of interest	Parenting in the NICU in particular, parents' needs and nursing behaviours that support these needs
<b>Search Details</b>	
Sources	Medline and CINAHL. Reference lists of included studies.
Range (years) of included studies	1998-2008
No. of studies	60
Types of studies included	Quantitative (n=30), qualitative (n=28), mixed-methods (n=2)
Country of origin of included studies	Predominantly US but also UK, Australia, Thailand, Canada, Sweden, Finland, The Netherlands, Brazil, Hong Kong, South Africa
<b>Appraisal</b>	
Appraisal instruments used	None detailed
Appraisal rating	None detailed
<b>Analysis</b>	
Method of analysis	"Conventional content analysis" undertaken after studies grouped as either addressing parenting needs (n=19), addressing supporting behaviours (n=24) or both (n=17) and then categorised as either quantitative, qualitative or mixed methods.
Outcome assessed	N/A
Results/findings	<p>Needs of parents:</p> <ul style="list-style-type: none"> <li>Desire for accurate information and inclusion in care and decision making was reported by many studies. Described feeling as though parenting at a distance and some felt excluded. Being able to provide basic care was critical.</li> <li>Need to be vigilant and watch over and protect the infant. As trusting relationships with healthcare providers formed, watchfulness began to relax.</li> </ul>

	<ul style="list-style-type: none"> <li>• Need for contact with the infant was reported by many studies. When holding not possible, mothers found comfort in sitting next to the bed and stroking the infant. Providing breastmilk was viewed as a form of contact and something mothers could do for their babies. Some parents reported inappropriate limits of contact with the bay and nurses hovering over them and the infant, resulting in feelings of frustration.</li> <li>• Need to be positively perceived by nursery staff. Did not want to appear difficult and felt had to be nice to nursing staff to maintain a good relationship and often the father voiced any complaints.</li> <li>• Need for individualized care and recognize needs of fathers.</li> <li>• Need for a therapeutic relationship with nursing staff. Nurses were found to positively or negatively influence the development of the parent-infant relationship. In some studies a power struggle was identified which was a result of inhibitive nursing practices and staff acting as gatekeepers.</li> </ul> <p>Behaviours that support parents:</p> <ul style="list-style-type: none"> <li>• Emotional support. Support from staff was found to be highly important. Several studies also identified peer support as being an effective strategy.</li> <li>• Parent Empowerment. This was acknowledged as being crucial but there was a lack of awareness on how to facilitate this.</li> <li>• Welcoming environment with supportive unit policies was seen as crucial. An engaging communication style was seen as being critical in developing the nurse-patient relationship. Some mothers were intimidated by the NICU environment so need to be supported to provide care.</li> <li>• Inconsistencies in how family centred care is conceptualised and implemented. Paediatric and those qualified &lt;10 years were more likely to rate FCC as important.</li> <li>• Parent education with an Opportunity to Practice New Skills Through Guided Participation. Having an opportunity to practice new skills with assistance from nursing staff was identified as important by parents. There are some specific interventions looking at this.</li> </ul>
Significance/direction	
<b>Comments</b>	Poor quality review

<b>Study Details</b>	1041
Author/year	De Rouk and Leys 2009
Review theme	Parental Experience
Objectives	To identify information and communication needs of parents of children admitted to the NICU and on their use of information sources in the illness trajectories at NICU.
Participants (characteristics/number)	Predominantly parents who had a child receiving NICU care. But also a few studies with obstetricians, nurses and physicians. Total no. not stated but mean sample size for quantitative studies was 147 (20-534) and for qualitative was 24
Setting/Context	NICU

Description of Interventions/ phenomena of interest	parental information needs and assess how the information needs and sources of parents change during and shortly after the stay of their infant at NICU.
<b>Search Details</b>	
Sources	Ovid Medline, PsycINFO, CINAHL and Sociological Abstracts
Range (years) of included studies	1990-2008
No. of studies	78
Types of studies included	53 studies used an observational design, 4 were RCTs, one quasi-experimental, four uncontrolled experimental, five descriptive of interventions. From all of these 20 studies were qualitative, 30 were quantitative, 14 used existing questionnaires and 12 mixed methods
Country of origin of included studies	United States (n = 35), United Kingdom (n = 8), Australia (n = 6) and Canada (n = 6). Also single studies from South Africa, Denmark, Thailand and sometimes not stated
<b>Appraisal</b>	
Appraisal instruments used	None stated
Appraisal rating	None stated
<b>Analysis</b>	
Method of analysis	Method of analysis not explicitly stated but information from studies is presented narratively
Outcome assessed	N/A
Results/findings	<p>Information sources:</p> <ul style="list-style-type: none"> <li>• Internal NICU sources including staff, printed materials, audio recordings of consultations and internet tools.</li> <li>• External sources: Other health professionals, peers, printed materials, TV/radio, internet</li> </ul> <p>Trajectory of information needs:</p> <ul style="list-style-type: none"> <li>• Limited information on parental needs and information provision</li> <li>• Neonatologists adapt information provision to convey uncertainty but this can be perceived as a focus on negative outcomes by parents</li> <li>• Information needs greatest at beginning but parents then learn medical language, how to respond to the needs of the child and how to gain information (e.g. attending rounds etc)</li> <li>• Information behaviour in sudden events and later phases receives limited attention</li> </ul>
Significance/direction	
<b>Comments</b>	Low quality review. No formal critical appraisal

<b>Study Details</b>	2512
Author/year	Obeidat et al. 2009
Review theme	Parental Experience.
Objectives	To explore and describe the experience of parents with an infant in the NICU (n=188) and nurses working in the NICU (n=31, only two studies)
Participants (characteristics/number)	Parents (predominantly mothers) of children in the NICU (n=188) and nurses working in the NICU (n=31, only two studies). Majority of participants were white, middle class families



Setting/Context	NICU
Description of Interventions/ phenomena of interest	Parents of experiences of NICU care
<b>Search Details</b>	
Sources	MEDLINE, CINAHL, Ebscohost, Hinari, BlackweU Synergy, Science Direct, OVID, and Highwire Stanford
Range (years) of included studies	1998-2008
No. of studies	14
Types of studies included	Qualitative
Country of origin of included studies	Not stated
<b>Appraisal</b>	
Appraisal instruments used	Not stated
Appraisal rating	Not stated
<b>Analysis</b>	
Method of analysis	Not stated but is narrative
Outcome assessed	N/A
Results/findings	<ul style="list-style-type: none"> <li>• Theme 1. Feelings of stress, strain, separation, depression, despair, disappointment, ambivalence, and lack of control over the situation:</li> <li>• Theme 2. Vacillation between hope and hopelessness</li> </ul>
Significance/direction	
<b>Comments</b>	Low quality review. No critical appraisal

<b>Study Details</b>	606
Author/year	Provenzi & Santoro, 2015
Review theme	Parental Experience.
Objectives	To systematically review the experience of fathers of preterm infants hospitalised in the Neonatal Intensive Care Unit
Participants (characteristics/number)	Fathers with infants receiving NICU care (n=264). Note that many studies also included mothers.
Setting/Context	NICU
Description of Interventions/ phenomena of interest	Fathers experiencing having a preterm infant requiring NICU care
<b>Search Details</b>	
Sources	CINAHL, WOS, PubMed, Scopus
Range (years) of included studies	2001-2013
No. of studies	14
Types of studies included	Qualitative (semi-structured interviews and ethnographic)
Country of origin of included studies	Germany, USA, Sweden, Canada, Norway, Iran, UK, France, Denmark
<b>Appraisal</b>	

Appraisal instruments used	JBI critical appraisal tool for qualitative studies
Appraisal rating	Studies were excluded if they failed to meet criteria. No study was excluded. The primary issues was a lack of statement locating the researcher culturally or theoretically and some studies did not consider reflexivity
<b>Analysis</b>	
Method of analysis	Content analysis
Outcome assessed	N/A
Results/findings	<p>Five main themes:</p> <ul style="list-style-type: none"> <li>• Emotional rollercoaster. Shock at birth. First worry is for partner and the baby. Feel left out and a sudden loss of control.</li> <li>• Parental needs. Fathers have a need to be informed and be actively engaged care but face barriers to this. Also need to be recognised as a father and not only as the partner of the mother.</li> <li>• Coping strategies. Some fathers coped by inhibiting negative feelings and focus on caring for the mother and infant. Going back to work also acting as a coping strategy as allowed fathers to gain a sense of self-confidence and competence. Also fears over income loss if do not return to work.</li> <li>• Self-representation. Fathers feel like an outsider and detached (perhaps due to lack of physical contact) but a growing sense of parenthood emerges across the NICU journey and transition to competent paternal self-representation can be fostered and sustained by direct engagement of fathers at the beginning.</li> <li>• Caregiving environment. Some scared of physical contact in case the baby is harmed but others frustrated by the lack of physical contact. Early interaction was described as a positive experience. Kangaroo care can help with the parenthood transition.</li> </ul>
Significance/direction	N/A
<b>Comments</b>	Adequate quality review

<b>Study Details</b>	2235
Author/year	Ribeiro et al. 2014
Review theme	Parental Experience.
Objectives	To analyse the scientific evidence on the Nursing care experienced at NICUs from the perspective of nurses and parents during their hospital stay at those units.
Participants (characteristics/number)	Parents whose infant had been hospitalised in a NICU for at least 24 hrs (n=87) and nurses working in NICUs (n=52)
Setting/Context	NICU
Description of Interventions/ phenomena of interest	Perceptions on the experiences and meanings assigned to care during the hospitalisation at a NICU
<b>Search Details</b>	
Sources	CINAHL; MEDLINE and Cochrane
Range (years) of included studies	2004-2013
No. of studies	9

Types of studies included	Qualitative
Country of origin of included studies	USA, England, Brazil, Portugal, Norway, Canada, Australia
<b>Appraisal</b>	
Appraisal instruments used	Not clear – states a grid previously designed to assess the rigor and quality of results was used
Appraisal rating	Not stated
<b>Analysis</b>	
Method of analysis	Thematic analysis
Outcome assessed	N/A
Results/findings	<p>Three themes:</p> <ul style="list-style-type: none"> <li>• Therapeutic Relationship. This evolved during the admission as nurses engage more with families and provide emotional support, facilitate information giving and guide procedures. It is a collaborative relationship in which the family and nurse have joint values and means of solving problems.</li> <li>• Humanisation of care. a new ethical approach that permeates all professional activities and institutional work processes, in addition to implying the provision of a dignified, supportive and welcoming nursing treatment and care</li> <li>• Suffering. Nursing procedures often appear to cause pain and discomfort which causes anxiety for the parents. Parents also experience panic and fear at the thought that the newborn may not survive.</li> </ul>
Significance/direction	N/A
<b>Comments</b>	Low quality review.

<b>Study Details</b>	641
Author/year	Rosenstock et al. & van Manen. 2014
Review theme	Parental Experience.
Objectives	To explore the literature pertaining to adolescent parenting in the NICU
Participants (characteristics/number)	Adolescent parents (10-19 years) with a child in the NICU
Setting/Context	NICU
Description of Interventions/ phenomena of interest	How the challenges of being an adolescent can make add complexity to parenting a preterm or sick infant in the NICU
<b>Search Details</b>	
Sources	MEDLINE, EMBASE, PubMed, CINAHL
Range (years) of included studies	1990-2013
No. of studies	22
Types of studies included	Qualitative and quantitative
Country of origin of included studies	US, Brazil, New Zealand, Turkey, Canada, UK (note predominantly US)
<b>Appraisal</b>	

Appraisal instruments used	Not stated
Appraisal rating	Not stated
<b>Analysis</b>	
Method of analysis	Not stated
Outcome assessed	N/A
Results/findings	<ul style="list-style-type: none"> <li>• Only one study was a qualitative exploration of parents' experiences which reported that teen mothers also expressed a need to engage in mother activities that might be facilitated or compromised by hospital staff. Medical staff need to facilitate engagement between the mother and child.</li> <li>• Majority of studies focused on parental stress/anxiety and found that adolescent parents do report stress and some studies reported these levels were greater than for older mothers (but these were small studies and other confounding factors may be present)</li> <li>• Parenting practices. Some studies reported that adolescent parents were more withdrawn. Access to the NICU was associated with more affectionate behaviours. Adolescent mothers were generally less likely to breastfeed.</li> <li>• Parent-staff communication and parental knowledge. Adolescent mothers were less likely to ask questions and less likely to place importance on needs.</li> <li>• NICU parental intervention studies. Two programmes were identified (Creating Opportunity for Parent Empowerment [COPE] and Teen Parent Support Programme). COPE was associated with decreased anxiety and evaluation of Teen Parent Support is necessary</li> </ul>
Significance/direction	N/A
<b>Comments</b>	Low quality review

<b>Study Details</b>	1466
Author/year	Swartz. 2005
Review theme	Parenting Preterm Infants: a meta-synthesis
Objectives	To synthesize the findings of qualitative studies on parenting preterm infants and present a framework that will enable clinical nurses to provide better care
Participants (characteristics/number)	Primary Caregivers (n=265). Primarily mothers but also fathers and grandmothers.
Setting/Context	Before and/or after discharge for the NICU
Description of Interventions/ phenomena of interest	Unique concerns of parents of preterm infants and how this can be generalized to improve care for them
<b>Search Details</b>	
Sources	CINAHL, MedLine, PsycInfo, SilverPlatter and Dissertation Abstracts
Range (years) of included studies	1990-2003
No. of studies	10
Types of studies included	Qualitative

Country of origin of included studies	Not stated
<b>Appraisal</b>	
Appraisal instruments used	Not stated
Appraisal rating	Not stated
<b>Analysis</b>	
Method of analysis	Meta-ethnography
Outcome assessed	N/A
Results/findings	<p>Five themes:</p> <ul style="list-style-type: none"> <li>• Adapting to risk. Parents had overwhelming concerns about the baby's health and development and this remained into toddlerhood.</li> <li>• Protecting Fragility. Parents described a sense of vulnerability which was closely tied with providing protection and shielding the infant from potential hazards. Some families felt a sense of being under surveillance.</li> <li>• Preserving the family. Stresses challenged their coping resources and brought about changes in role relationships. Higher levels of communication were necessary.</li> <li>• Compensating for the past. Parents viewed their children as both normal and special and afforded them some leniency when misbehaving.</li> <li>• Cautiously affirming the future. As parents emerged from the initial stages they started to reconnect with friends and reaffirm their family unit. For some families it was difficult to grasp their infants actual age.</li> </ul>
Significance/direction	N/A
<b>Comments</b>	Low quality review

<b>Study Details</b>	2214
Author/year	Sisson et al. 2013
Review theme	Parents' experiences of care
Objectives	To synthesize existing qualitative findings about fathers' experiences of the neonatal intensive care unit (NICU) environment.
Participants (characteristics/number)	Fathers with preterm infants receiving NICU care (n=211)
Setting/Context	NICU
Description of Interventions/ phenomena of interest	an understanding of the experiences of fathers in the NICU
<b>Search Details</b>	
Sources	CINAHL, MEDLINE, PsycINFO. Reference lists searched.
Range (years) of included studies	2005-2013
No. of studies	24
Types of studies included	Qualitative

Country of origin of included studies	Not stated but 12 different countries included
<b>Appraisal</b>	
Appraisal instruments used	CASP
Appraisal rating	Authors state they reached consensus that the studies appeared to be of a reasonable quality with some limitations
<b>Analysis</b>	
Method of analysis	Meta-ethnography
Outcome assessed	N/A
Results/findings	<p>Five key concepts:</p> <ul style="list-style-type: none"> <li>• Proximity. Fathers expressed a need for proximity to their child as it enabled them to feel they were fulfilling a paternal role. Barriers to this included fragility of the infant and equipment. Facilitators to this were staff and receiving information.</li> <li>• Parental Autonomy. Data embodied a paradox of the right to exercise parental autonomy with the need to hand the care over to the NICU staff. Parental autonomy was influenced by various factors and perceived to be significant element of fatherhood.</li> <li>• Vulnerability. Fathers vulnerability seemed to stem from being in an unfamiliar situation and a fear of harming the baby. Also do not want to be perceived as vulnerable or weak and felt they had to be the strong family member.</li> <li>• Communication. Sufficient, consistent information from available staff members was viewed as important in having a positive experience.</li> <li>• Exclusion and isolation. Some fathers felt disregarded and out on the sidelines and needs of mothers overshadowed the needs of the father. This may have implications on the father's self-esteem of being a parent.</li> </ul>
Significance/direction	N/A
<b>Comments</b>	High quality review

## Appendix 3.2 Service Configuration data extraction tables

<b>Study Details</b>	976
Author/year	Lasswell et al. 2015
Review theme	Service configuration
Objectives	To evaluate published data on associations between hospital level at birth and neonatal or pre-discharge mortality for VLBW and very preterm (VPT) infants.
Participants (characteristics/number)	Very low birth weight (<1500g) or very preterm (<32 weeks) live born infants, born in or after 1976. VLBW infants (high and sufficient quality studies only) = 46 318 Very preterm infants (high and sufficient quality studies only) = 6100
Setting/Context	Level III NICU units and units with a lower designated level of care
Description of Interventions/ phenomena of interest	The relationship between hospital level at birth and neonatal mortality for very preterm and very low birth weight infants
<b>Search Details</b>	
Sources	Medline (Ovid), CINAHL, PubMed, EMBASE and reference lists of included studies
Range (years) of included studies	1976 and 2010
No. of studies	37 studies for very low birth weight infants 4 studies for very preterm infants
Types of studies included	randomized controlled trial, prospective cohort, retrospective cohort, and case-control study designs
Country of origin of included studies	22 studies conducted in the US and 15 conducted in Canada, Ghana, Israel, Australia, and Europe
<b>Appraisal</b>	
Appraisal instruments used	No formal tool detailed. Studies were assessed by three reviewers on the level of adjustment for confounding and description of level of care designations and/or hospital care capabilities. Based on this studies were graded as either high, sufficient or low quality. On high and sufficient quality studies were included in the meta-analysis.
Appraisal rating	Very low birth weight, adequate or high quality, n=9, insufficient quality, n=28 Very preterm infants, adequate or high quality, n=3, insufficient quality, n=1
<b>Analysis</b>	
Method of analysis	Meta-analysis (random effects model)
Outcome assessed	Neonatal mortality
Results/findings	<ul style="list-style-type: none"> <li>• VLBW. 60% increase in neonatal mortality for those not born at a level III hospital. 36% vs 21%; adjusted OR, 1.60; 95% CI, 1.33-1.92. Statistical heterogeneity, Q=39.11; P &lt; .001</li> <li>• Extremely LBW infants (&lt;1000g). 80% increase in neonatal mortality for those not born at a level III hospital. 59% vs 32%; adjusted OR, 1.80; 95% CI, 1.31-2.46. Statistical heterogeneity Q=28.40; P &lt; .001</li> <li>• Very preterm. 42% increase in neonatal mortality for those not born at a level III hospital. 7% vs 12%; adjusted OR, 1.42; 95% CI, 1.06-1.88. No heterogeneity, Q=2.31; P=.31.</li> </ul>

	<ul style="list-style-type: none"> <li>Subgroup analysis. No significant between group differences were found based on study design, use of population-based or non-population-based data, data source, US or non-US location, outcome variable, birth weight range, inclusion of infants smaller than 500 g, or extent of control for confounding (P.05 for all).</li> </ul>
Significance/direction	Supports level III care for VLBW and very preterm infants. Significant.
<b>Comments</b>	Adequate quality. Majority of VLBW studies excluded due to being classified as poor quality. No formal critical appraisal tool used.

<b>Study Details</b>	1225
Author/year	Mori et al. 2007
Review theme	Service configuration
Objectives	To investigate the association between duration of inter-facility transport and perinatal mortality
Participants (characteristics/number)	Newborn infants <28 days (n=100)
Setting/Context	An aspect of regionalization of neonatal care services in a low income population dense urban area in India. Transport included ambulance and rickshaws
Description of Interventions/ phenomena of interest	Duration of inter-facility transport of newborn infants and the effect this has on infant mortality.
<b>Search Details</b>	
Sources	Medline, CENTRAL, EMBASE, CINAHL, BNI. Reference list searching.
Range (years) of included studies	1966-2004
No. of studies	1
Types of studies included	Historical cohort study
Country of origin of included studies	India
<b>Appraisal</b>	
Appraisal instruments used	No detail of a specific instrument. Quality assessment of studies included health-care setting, definition of the population, and validity of all variables including exposure status, outcome and other covariables. Special attention was paid to the assessment of confounding, bias and chance within each published study.
Appraisal rating	High probability of bias
<b>Analysis</b>	
Method of analysis	
Outcome assessed	Mortality, death in first week of life, death in the first 28 days of life, death up to time of hospital discharge, morbidity, interventricular, chronic lung disease, necrotising enterocolitis, proven systematic infection and neurodevelopmental abnormalities
Results/findings	<ul style="list-style-type: none"> <li>Neonates with a long duration of transport (undefined) had 79% higher odds of death than those with a short duration (CI: 1.38-8.42) after adjusting for the confounding effects of admission</li> </ul>



	weight, hypothermia, hypoglycemia, delayed capillary filling time, cyanosis and prematurity
Significance/direction	Positive and significant
<b>Comments</b>	<p>This is a moderately well conducted review but it only identified one study which had a lot of missing data and is from a setting that may not be applicable to a Scottish context.</p> <p>Note that this paper also presents results from a cohort study that the authors conducted in Japan. This included 16429 infants and after controlling for confounding variables identified that infants who transported for &gt;90 minutes by ground ambulance had a RR of 2.26 (CI: 1.26-4.04) and those who travelled for between 60-89 minutes had a RR of 1.81 (CI: 1.07-3.06) compared to those transported between 30 and 59 minutes</p>

<b>Study Details</b>	829
Author/year	Neogi et al. 2012
Review theme	Service configuration
Objectives	To assess different factors that affect effectiveness of facility based newborn care on neonatal outcomes. Note this review looked at a range of components but this extraction will focus on the regionalization of perinatal care component.
Participants (characteristics/number)	Newborns requiring hospital care
Setting/Context	Regionalized system of perinatal care in developing and developed countries
Description of Interventions/ phenomena of interest	To assess different factors that affect neonatal outcomes in facilities providing newborn care and parameters that influence the performance of the facilities
<b>Search Details</b>	
Sources	Pubmed, IndMed, BioMed Central, Cochrane, PopLine and Google. Relevant websites were checked and grey literature and journal handsearching was conducted
Range (years) of included studies	1966-2010
No. of studies	17
Types of studies included	Observational and interventional studies
Country of origin of included studies	Not fully detailed but review makes reference to studies in US, UK and Portugal
<b>Appraisal</b>	
Appraisal instruments used	None detailed
Appraisal rating	None detailed
<b>Analysis</b>	
Method of analysis	Narrative
Outcome assessed	N/A
Results/findings	<ul style="list-style-type: none"> <li>Regionalization increased the in-utero transfer of high risk newborns and improved survival chances especially of VLBW infants which led to a reduction in neonatal mortality</li> </ul>

	<ul style="list-style-type: none"> <li>High patient volume (&gt;2,000 deliveries/ year), inborn status, availability of referral system and inter-facility transfers, and adequate nursing care staff in neonatal units also demonstrated protective effect in averting neonatal deaths</li> </ul>
Significance/direction	N/A
<b>Comments</b>	Low quality review with no formal critical appraisal conducted

<b>Study Details</b>	1816
Author/year	Rashidian et al. 2014
Review theme	Service configuration
Objectives	To assess whether the existing evidence from interventional studies can provide robust evidence on the effectiveness of perinatal regionalization on improving maternal and neonatal health outcomes (i.e. mortality and morbidity). The secondary objective of this study was to assess whether different varieties of 'perinatal regionalization' differ in their effectiveness.
Participants (characteristics/number)	6 studies included all births between particular time periods. One study specifically looked at very preterm and one specifically looked at very low birth weight
Setting/Context	Perinatal services in provincial (n=3) regional (n=3) and rural (n=2)
Description of Interventions/ phenomena of interest	Impact of perinatal regionalization on neonatal morbidity and mortality
<b>Search Details</b>	
Sources	MEDLINE, EMBASE, HMIC, EconLit
Range (years) of included studies	1977-2010
No. of studies	8
Types of studies included	ITS (n=3), CBA (n=1), uncontrolled before-after (n=4)
Country of origin of included studies	USA (n=6), Canada (n=1), France (n=1)
<b>Appraisal</b>	
Appraisal instruments used	Cochrane EPOC risk of bias tool for before-and-after studies and ITS
Appraisal rating	Risk of bias high in 5 out of the 8 studies
<b>Analysis</b>	
Method of analysis	Narrative
Outcome assessed	Neonatal mortality, perinatal mortality, LBW, still births, deliveries in level III centres, fetal mortality, infant mortality, low 5 min Apgar Score, motor development and maternal sensitivity or involvement
Results/findings	<ul style="list-style-type: none"> <li>Neonatal mortality. 7/8 studies reported a reduction but this was only significant in 3.</li> <li>Perinatal mortality. 3/8 studies reported a reduction but none significant.</li> <li>LBW. 4/8 studies reported a reduction</li> <li>Still birth. 2/8 studies reported a reduction but this was not significant</li> <li>LBW delivery in level III centres. 4 studies reported an increase but this was only significant in 2.</li> </ul>

	<ul style="list-style-type: none"> <li>• Fetal mortality. 2/8 studies reported a reduction but this was only significant in 1.</li> <li>• Infant mortality. 1/8 studies reported a reduction which was significant</li> <li>• Low 5 min Apgar Score. 2/8 studies reported a reduction and significant in both</li> <li>• Motor development. 1/8 studies reported a reduction which was not significant</li> <li>• Maternal sensitivity or satisfaction. 1/8 studies reported an increase which was significant</li> </ul>
Significance/direction	
<b>Comments</b>	Review is of adequate quality but the actual evidence is limited as 5 studies were high risk of bias and with the exception of two, all were published before 1990 and 6/8 were published in the US.

<b>Study Details</b>	2814
Author/year	Chang et al. 2015
Review theme	Service configuration
Objectives	To determine the effects of specialist transport teams compared with non-specialist transport teams on the risk of neonatal mortality and morbidity among high-risk newborn infants requiring transport to neonatal intensive care.
Participants (characteristics/number)	neonates requiring transport to a neonatal intensive care unit (no studies identified so n=0)
Setting/Context	Transport to NICU
Description of Interventions/ phenomena of interest	Transport by a specialist team compared to a non-specialist team
<b>Search Details</b>	
Sources	CENTRAL, MEDLINE, EMBASE, CINAHL, conference proceedings and reference lists
Range (years) of included studies	Inception-2015
No. of studies	0
Types of studies included	Would have included randomised, quasi-randomised or cluster randomised controlled trials
Country of origin of included studies	
<b>Appraisal</b>	
Appraisal instruments used	Cochrane ROB tool
Appraisal rating	N/A
<b>Analysis</b>	
Method of analysis	N/A
Outcome assessed	death; adverse events during transport leading to respiratory compromise; and condition on admission to the neonatal intensive care unit
Results/findings	N/A
Significance/direction	N/A

<b>Comments</b>	High quality review which did not identify any randomised , quasi-randomised or cluster randomised controlled trials in this field.
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## Appendix 3.3 Methods for Improving Family Centred Care Data Extraction

<b>Study Details</b>	1830
Author/year	Chan et al. 2015
Review theme	Methods for Improving Family Centred Care
Objectives	To investigate factors influencing the adoption of kangaroo mother care in different contexts.
Participants (characteristics/number)	mothers, newborns or mother-newborn dyads who had practiced kangaroo mother care, and health-care providers, health facilities, communities and health systems that have implemented such care. Did include preterm and LBW infants but also included studies with term and normal birthweights. Not stated how many but 60% of studies had <50 participants
Setting/Context	NICU, stepdown unit, health facility, community
Description of Interventions/ phenomena of interest	To understand the reasons behind poor uptake of kangaroo mother care, which was defined as including early and continuous skin-to-skin contact, breastfeeding, early discharge from the health-care facility and supportive care
<b>Search Details</b>	
Sources	PubMed, Embase, Web of Science, Scopus, African Index Medicus (AIM), Latin American and Caribbean Health Sciences Literature (LILACS), Index Medicus for the Eastern Mediterranean Region (IMEMR), Index Medicus for the South-East Asian Region (IMSEAR) and Western Pacific Region Index Medicus (WPRIM). Reference checking of systematic reviews and included studies
Range (years) of included studies	1960-2015 (most from >2010)
No. of studies	112
Types of studies included	Qualitative
Country of origin of included studies	Data limited to: WHO Americans Region (36%), WHO African Region (26%) and also in the WHO European, South-East, Eastern Mediterranean, Western Pacific
<b>Appraisal</b>	
Appraisal instruments used	Domain based approach
Appraisal rating	60% appropriately address 4 out of the 5 domains
<b>Analysis</b>	
Method of analysis	Narrative analysis guided by a conceptual framework
Outcome assessed	N/A
Results/findings	<ul style="list-style-type: none"> <li>• Lack of standardized definition makes implementation challenging</li> <li>• Buy-in and bonding: acceptance of kangaroo mother care, belief in the benefits of such care to mothers and preterm or low birthweight infants and reported perceptions of bonding. Lack of belief in KC by staff restricted its uptake. Good support from management helped implemented KC</li> <li>• Social support: Staff shortages and less prioritisation of KC acted as a barrier to providing support. Peer support in the ward helped promote KC.</li> </ul>

	<ul style="list-style-type: none"> <li>• Time: time needed acted as a barrier due to other responsibilities of parents and also prevented staff from helping. This could be helped by extending visiting times</li> <li>• Medical concerns: condition of mother and/or infant may prevent kangaroo care. Knowledge that kangaroo mother care supported newborns in stabilizing their temperatures, helped with</li> <li>• breathing and promoted mother–child bonding, encouraged its use</li> <li>• Access: lack of money for transportation and the distance to hospital, lack of private space within the hospital but Uptake improved with transportation for mothers not staying at the hospital, wrappers to hold the baby, furniture/ beds where mothers could conduct kangaroo mother care, rooms where mothers could spend the night with the baby</li> <li>• Context: Sociocultural context and sociocultural constructs of gender and roles of parents in childcare, men in the household and other family members influenced uptake</li> </ul>
Significance/direction	N/A
<b>Comments</b>	Adequate quality systematic review but a considerable proportion of included studies were of low quality

<b>Study Details</b>	2482
Author/year	Kearvell and Grant. 2010
Review theme	Methods for Improving Family Centred Care
Objectives	To explore how nurses can support the mother-infant dyad within the neonatal intensive care unit.
Participants (characteristics/number)	Mothers with infants in the NICU or nurses working within the NICU. Number of participants not stated.
Setting/Context	NICU (care provided primarily in this setting)
Description of Interventions/ phenomena of interest	How nurses implement support to help bonding and the development of the parent-infant relationship
<b>Search Details</b>	
Sources	CINAHL, PubMed, WOS
Range (years) of included studies	1998-2008
No. of studies	15
Types of studies included	Qualitative (n=13) and mixed methods (n=2)
Country of origin of included studies	Not stated
<b>Appraisal</b>	
Appraisal instruments used	CASP for qualitative studies. These were further evaluated using categories of credibility, fittingness, auditability and conformability to determine rigour or 'validity and reliability'. University of Salford evaluation tool for mixed methods studies
Appraisal rating	Not reported
<b>Analysis</b>	
Method of analysis	Thematic analysis
Outcome assessed	N/A

Results/findings	<p>Mother-infant interaction can be supported in three ways by nursing staff:</p> <ul style="list-style-type: none"> <li>• Kangaroo Care. Enabled physical contact and strengthened attachment in an environment that inhibits this. KC enhanced maternal confidence. Benefits of KC recognised by nurses but they were concerned about their capacity to implement it due lack of space, fear of dislodging equipment and staff shortages.</li> <li>• Breastfeeding. Gave mothers a feeling of importance and normality. Enhanced attachment.</li> <li>• Participation in routine care. Nurse could facilitate attachment by encouraging touching, talking, comforting, changing nappies, feeding, turning their infant and responding to behavioural cues. Not all mothers have confidence to do this and was only possible with a positive and shared attitude of the nurse. Mothers involved in care were enabled to take up authority as mother and make decisions about care.</li> </ul> <p>Mother-nurse interaction:</p> <ul style="list-style-type: none"> <li>• Psychosocial support. nurses who provided support, assistance, privacy and had a positive and encouraging attitude towards mothers throughout their experience helped to alleviate maternal anxiety. Mothers gained satisfaction and confidence from nurses who provided education, guidance, encouragement and emotional support throughout new experiences in the neonatal intensive care unit</li> </ul> <p>Communication. Provision of constant updates helped mothers understand the baby's health needs which eased anxiety. Chatting could help mothers feel relaxed and establish confidence in the unit and facilitate connectedness</p>
Significance/direction	
<b>Comments</b>	Results of critical appraisal were not detailed so review is of low quality

<b>Study Details</b>	1489
Author/year	Koh et al. 2005
Review theme	Methods for Improving Family Centred Care
Objectives	To assess the usefulness of providing parents of sick babies with audiotape recordings of their consultations with neonatologists.
Participants (characteristics/number)	Parents of babies admitted to NICU. Parents of both single and multiple pregnancies were eligible. There were no restriction on postnatal age at entry
Setting/Context	NICU
Description of Interventions/ phenomena of interest	Providing parents of babies in NICU with audio recordings of their initial conversation with doctors in NICU and subsequent conversations considered significant by the doctors, e.g. discussion about conditions such as cerebral insults, seeking of informed consent
<b>Search Details</b>	
Sources	Oxford Database of Perinatal Trials, CENTRAL, Ovid MEDLINE, CINAHL< PsycINFO, APAIS-Health, Health and Society, WOS, ISI, JBI, Ovid EBM Reviews ACP Journal Club, Proquest Dissertations, NYAM, Google.

	Reference lists of included studies searched, experts contacted, hand searching of the abstracts and conference proceedings of the annual meetings of the Society for Pediatric Research (1990 to February 2004) and The European Society for Paediatric Research (1990 to February 2004). Used Cochrane Neonatal Group Search Strategy
Range (years) of included studies	1966-2004
No. of studies	0
Types of studies included	Randomised or quasi-randomised trials
Country of origin of included studies	N/A
<b>Appraisal</b>	
Appraisal instruments used	Cochrane ROB
Appraisal rating	N/A
<b>Analysis</b>	N/A
Method of analysis	
Outcome assessed	Primary outcomes: Use of tapes and information recall or understanding, experience of health care and parental health and wellbeing. Data about participants' uses and opinions of their recordings and summaries were also extracted. Secondary Outcomes: psychological morbidity such as post-natal depression, general health, anxiety state and coping / parenting ability of parents and involvement of other family members using the recordings
Results/findings	No studies identified so no evidence to support use of recording conversations
Significance/direction	
<b>Comments</b>	High quality Cochrane review but no studies identified

<b>Study Details</b>	836
Author/year	Shahheidari & Homer. 2012
Review theme	Methods for Improving Family Centred Care
Objectives	To describe the main features of NICU design and determine the advantages and limitations of the design in terms of outcomes for babies, parents, and staff.
Participants (characteristics/number)	Staff working in NICUs Neonates cared for in NICUs (number not stated)
Setting/Context	
Description of Interventions/ phenomena of interest	Examining the benefits of different designs e.g. open bay vs single room and the positive and negative design features.
<b>Search Details</b>	
Sources	MEDLINE, CINAHL, Science Direct, Cochrane Library. Reference lists of included articles.
Range (years) of included studies	2000-2011
No. of studies	12



Types of studies included	Controlled trials, cohort studies, before-and-after studies, cross-sectional survey, qualitative
Country of origin of included studies	US, Turkey, Sweden, Taiwan, Denmark (mainly US)
<b>Appraisal</b>	
Appraisal instruments used	Not stated
Appraisal rating	Not stated
<b>Analysis</b>	
Method of analysis	Narrative
Outcome assessed	Primary outcomes: Staff stress and effectiveness in delivering care; Patient safety; Health outcomes and Overall healthcare quality Secondary outcomes: Infection control; Length of stay and rehospitalisation; noise on neonates; Workload and communication between staff; Privacy and comfort for parents
Results/findings	<ul style="list-style-type: none"> <li>• Patient medical progress including infection control. Infants in single family rooms consistently had reduced infection</li> <li>• Length of stay. Single family rooms were associated with a shorter stay in NICU and decreased risk of re-admission (authors hypothesise this may be mediated by kangaroo care and breastfeeding which are easier in single family rooms)</li> <li>• Noise. Identified as a stressor to infants, staff and family. Noise levels found to be lower in single rooms.</li> <li>• Workload and communication. Single family rooms were reported to be harder to manage by nursing staff in terms of communication between staff and monitoring the infants</li> <li>• Privacy and comfort. Parents reported increased privacy and feeling more like a family</li> </ul>
Significance/direction	Significance levels not reported. Supports single family rooms.
<b>Comments</b>	Low quality review

<b>Study Details</b>	2360 and 2795
Author/year	Staniszewska et al. 2012 Brett et al. 2011
Review theme	Family centred care
Objectives	To develop the first international model of family-centred care based on strong parental collaboration in the synthesis of robust research evidence to generate the philosophy, principles, model, and indicators for implementation.
Participants (characteristics/number)	Parents who had a preterm infant (<36 weeks) requiring NICU care. Authors note that certain groups were under-represented in the study samples: these included minority ethnic, disadvantaged groups, and young parents
Setting/Context	Neonatal units in developed countries
Description of Interventions/ phenomena of interest	Model of family centred care. Note also includes a qualitative study.
<b>Search Details</b>	
Sources	Medline, Embase, PsychINFO, the Cochrane library, CINHAL,

	MIDIRS, HMIC, and HELMIS. Grey literature was sought and the Neonatal Network Journal, Journal of Neonatal Nursing and Journal of Obstetric, Gynecologic, and Neonatal Nursing were hand searched
Range (years) of included studies	1980-2009
No. of studies	19 RCTs, 16 cohorts, 37 non-intervention studies
Types of studies included	CTs, quasi-experimental, cohort, case control, cross-sectional, case series, case reports or qualitative;
Country of origin of included studies	
<b>Appraisal</b>	
Appraisal instruments used	SIGN was used to grade the evidence.
Appraisal rating	RCTs for supporting parents through individualised developmental and behavioural care programmes were graded 1++ or 1+
<b>Analysis</b>	
Method of analysis	Non-quantitative synthesis
Outcome assessed	N/A
Results/findings	<p>The following types of intervention studies were identified:</p> <ul style="list-style-type: none"> <li>• Supporting parents through individualised developmental and behavioural care programmes (n=14, including 9 RCTs). The RCTs suggested that these programmes decreased maternal stress and improved parental understanding and interaction. Qualitative studies reported that such programmes could empower parents and promote self-reliance and decrease stress</li> <li>• Supporting parents through the use of behavioural assessment scales (n=3). No RCTs reported on this. Three cross-sectional studies taught parents how to administer the Brazelton Scale and reported that it may improve mother-infant bonding, reduce maternal anxiety and help mothers foster a realistic perception of their infant.</li> <li>• Supporting parents through breastfeeding, kangaroo care and infant massage. <ul style="list-style-type: none"> <li>○ Five studies (1 RCT, 3 cross-sectional and 1 case series) reported on breastfeeding. The RCT reported no change in outcomes but the other studies reported that mothers receiving breastfeeding support were more likely to continue 1 month after discharge.</li> <li>○ Six studies (2 RCTs, 1 cohort, 1 cross-sectional, 2 qualitative) reported on kangaroo care. The RCTs reported that kangaroo care reduces anxiety and gives a greater sense of competence and sensitivity towards the infant. In the other studies kangaroo care was associated with interaction and better maternal wellbeing</li> <li>○ Baby Massage (1 RCT, 1 cross-sectional) was associated with improved maternal-infant interactions</li> </ul> </li> <li>• Support forums for parents. No RCT evidence but cohort, qualitative and cross-sectional studies identified that peer led programmes help with stress and provided emotional and practical support. Professional-led programmes were also associated with reduced anxiety and gains in confidence.</li> </ul>

	<ul style="list-style-type: none"> <li>• Alleviating parent stress. The individualised developmental behavioural programme helped reduce parental stress. One RCT also reported the use of videotape in strategies that focus on coping with emotions and active problem-solving. A cohort study reported that one-off psychological interventions to teach relaxation and coping mechanisms to normalise their experience, as well as emotional and practical support, was associated with a reduction in traumatic impact.</li> <li>• Preparing parents for seeing their infant in the NICU for the first time (1 RCT, 1 qualitative). The RCT reported that giving parents a photograph of their preterm infant provides a positive effect by improving bonding with their infant. The qualitative study examined the impact of touring the NICU prior to birth (in high risk women). For some parents this was a positive experience which provided reassurance but for others it was overwhelming.</li> <li>• Interventions for communication and information sharing (n=8, 1 RCT, 2 cohort, cross-sectional and 3 qualitative). The RCT reported that taping parent–doctor consultations improved the recall of parents of the consultation. Effective communication was perceived as discourse management, caring and reassuring communication and communication as equal partners. Social talk between nurses and parents also had a positive influence. Ineffective communication was perceived as when the information given was inconsistent, when staff did not check if parents understood the information and when questions were not allowed. BabyLink (web-based programme) helped to provide individualised information to parents helped communicate complex issues, and parents reported that it helped to humanise the experience of the NICU.</li> <li>• Discharge Planning (n=6, 1 RCT). The 1 RCT reported that a discharge planning model improved parents' engagement and interactions with their infants. Qualitative studies reported that discharge support programmes helped contribute to a feeling of overall increased support and met their needs, including improving their confidence in caring for their preterm infant and ensuring the well-being of their child following discharge. Early discharge helped parents feel like a normal family but families appreciated having 24 h accessibility to the NICU staff.</li> <li>• Home Support Programmes (n=10, 2 RCTs). The RCT evidence reported that programmes which give regular parental support for 1-3 years were associated with increased maternal responsiveness and reduced stress but no effect on maternal coping. Similar evidence found in cohort studies. Specific to the UK, the community neonatal service was valued positively in providing support and continuity of care for parents who needed a high level of support (e.g. experiencing depression, bonding struggles with their infant, infant-sleeping issues and feeding problems)</li> </ul>
Significance/direction	N/A
<b>Comments</b>	Poor quality review

<b>Study Details</b>	2796
Author/year	Renfrew et al. 2009
Review theme	Methods for Improving Family Centred Care
Objectives	To evaluate the effectiveness and cost effectiveness of interventions that promote or inhibit breastfeeding or feeding with breastmilk for infants admitted to neonatal units
Participants (characteristics/number)	Women with a child receiving NICU care
Setting/Context	NICU or post-discharge from NICU
Description of Interventions/ phenomena of interest	Any intervention that addressed breastfeeding/feeding with breastmilk in neonatal units, or studies that comprised a home support component following discharge from the unit
<b>Search Details</b>	
Sources	EMBASE, CINAHL, Maternity and Infant Care, PsycINFO, British Nursing Index and Archive, Health Management Information Consortium, Cochrane Central Register of Controlled Trials, Science Citation Index, Pascal, Latin American and Caribbean Health Sciences, MetaRegister of Controlled Trials, Cochrane Database of Systematic Reviews, Database of Abstracts of Reviews of Effectiveness, Health Technology Assessment Database, National Research Register
Range (years) of included studies	Inception - 2008
No. of studies	48
Types of studies included	RCTs (n=31) and non-RCTs were considered first when available. If not none existed then other study designs were included (i.e. cross-over studies, repeated measures, cross-sectional before and after)
Country of origin of included studies	UK (n=8), Malaysia, India, USA, Australia, Mexico, USA, Ecuador, UK, Colombia
<b>Appraisal</b>	
Appraisal instruments used	Domain based assessment. Based upon CRD report no.4, NICE and Cochrane ROB tool
Appraisal rating	7 studies rated as good quality, 28 as a moderate quality and 13 as poor quality.
<b>Analysis</b>	
Method of analysis	Narrative
Outcome assessed	Breastfeeding initiation and duration
Results/findings	<p>Nine groups of interventions were identified:</p> <ul style="list-style-type: none"> <li>• Increased mother and baby contact (9 RCTs, 2 before and after study and one cross over study). Strong evidence that short periods of kangaroo care (up to 1hr) increased the duration of breastfeeding up to 1 month post discharge (RR: 4.76, CI: 1.19-19.10) and for more than 6 months (RR: 1.95, CI: 1.03 to 3.70) in clinically stable infants.</li> <li>• Interim feeding methods an (5 RCTs, 1 cross over study). Limited evidence for used of cup vs bottle feeding but it may increase breastfeeding at discharge and reduce the frequency of oxygen desaturation. No evidence to support the use of gavage feeding vs bottle feeding or use of caregivers fingers as pacifiers</li> <li>• Methods of expressing breastmilk (5 RCTs, 1 cross-over). Simultaneous pumping with an electric pump has advantages in</li> </ul>

	<p>the first two weeks. After discharge mother may also benefit from a hand pump or hand expression.</p> <ul style="list-style-type: none"> <li>• Enhancing breastmilk production (5 RCTs, 2 crossover studies). No evidence for galactagogues for mothers who have recently given birth but may have some benefit later if milk production not meeting infant's needs.</li> <li>• Supporting optimal nutritional intake from breastmilk (2 RCTs, 1 concurrent comparison). Good quality evidence lacking.</li> <li>• Breastfeeding Education and support (3 RCTs, 3 before after/studies). Strong evidence for effectiveness of peer support at home (from Manila) for mothers of term, LBW babies (RR: 2.18, CI: 1.45 to 3.29) and exclusive breastfeeding from birth to 6 months (RR: 65.94, CI: 4.12 to 1055.70). Strong evidence for effectiveness of peer support in hospital and at home for mothers of infants in SCBUs on providing any breast milk at 12 weeks (OR: 2.81, CI: 1.11-7.14). Limited evidence for effectiveness for skilled professional support in a US NICU on infants receiving any breastmilk at discharge (OR: 2.0; CI: 1.2-3.2).</li> <li>• Staff training (2 before and after studies). Limited evidence that educational interventions may increase staff knowledge and can increase initiation rates and breastfeeding. Lack of staff training can act as a barrier.</li> <li>• Early hospital discharge. Very limited evidence that this may adversely affect duration of breastfeeding but may decrease risk of infection.</li> <li>• Organisation of care (4 before and after studies). BFI accreditation was associated with increase in number of infants receiving any breastmilk.</li> <li>• Economic analysis found that additional skilled professional support in hospital was more effective and less costly than normal staff contact, due to decreased neonatal illness (0.009-0.251 QALYs per infant, £66-586 cheaper per infant across different birthweight populations).</li> </ul>
Significance/direction	Supports use of kangaroo care, peer support, simultaneous breast pumping, staff training and BFI.
Comments	High quality review

<b>Study Details</b>	2278
Author/year	Conde-Agudelo & Diaz-Rossello. 2014
Review theme	Methods for Improving Family Centred Care
Objectives	To determine whether there is evidence to support the use of KMC in LBW infants as an alternative to conventional neonatal care
Participants (characteristics/number)	LBW Infants (n=2751).
Setting/Context	NICU
Description of Interventions/ phenomena of interest	KMC defined as skin-to-skin contact between a mother and her newborn, frequent and exclusive or nearly exclusive breastfeeding, and early discharge from hospital
<b>Search Details</b>	
Sources	MEDLINE, CINAHL, EMBASE, LILACS, POPLINE and CENTRAL

Range (years) of included studies	
No. of studies	18
Types of studies included	RCTs included cluster controlled trials
Country of origin of included studies	Not stated
<b>Appraisal</b>	
Appraisal instruments used	Domain based appraisal. Cochrane ROB tool.
Appraisal rating	No study adequately address all 7 domains and only two addressed 6 domains so evidence described as mixed.
<b>Analysis</b>	
Method of analysis	Meta-analysis
Outcome assessed	Primary outcomes: Mortality, severe infection/sepsis, severe illness, infant growth, neurodevelopmental and neurosensory impairment Secondary outcomes: nosocomial infection/sepsis, mild/moderate infection or illness, lower respiratory tract disease, diarrhoea, hypothermia, hyperthermia, length of hospital stay, readmission to hospital, breastfeeding, mother-infant attachment, mother-infant interaction, parental and familiar satisfaction, home environment and father involvement, costs of care.
Results/findings	<ul style="list-style-type: none"> <li>○ Discharge or 40-41 weeks postmenstrual age reported in 8 trials (1736 infants) = significant decrease in mortality, RR 0.60, CI 0.39-0.92.</li> <li>○ Latest follow-up reported in 11 trials (2167 infants) = significant decrease in mortality, RR 0.67, CI 0.48-0.95)</li> <li>○ Nosocomial infection/sepsis RR =0.45, CI 0.27-0.76</li> <li>○ Hypothermia. RR 0.34, CI 0.17-0.67</li> <li>○ Length of hospital stay. Typical mean difference = 2.2 days, CI 0.6-3.7</li> <li>○ At latest follow-up = significant decreased risk of mortality, RR 0.67 CI 0.48-.95 in 11 trials</li> <li>○ Severe infection/sepsis = significant decrease, RR 0.56 CI 0.40-0.78</li> </ul> <p>Also significant improvements in weight, head circumference, and length gain, breastfeeding, mother satisfaction with method of infant care, some measures of maternal-infant attachment, and home environment. No difference in neurosensory or neurodevelopmental outcomes.</p>
Significance/direction	Supports KMC
<b>Comments</b>	High quality review

<b>Study Details</b>	2812
Author/year	Gray & Flenady. 2011
Review theme	Methods for Improving Family Centred Care
Objectives	To assess effects of cot-nursing versus incubator care on temperature control and weight gain in preterm infants
Participants (characteristics/number)	Preterm infants <37 weeks (includes both appropriate and small for gestational age infants). N=247
Setting/Context	Neonatal units

Description of Interventions/ phenomena of interest	Using cots instead of incubators, allows mothers to have easier access to their babies, however, methods for additional warmth are needed for temperature control. This review compared methods for providing additional warmth including extra clothing/bedding, space heated room, heating element below the mattress or a heated water filled mattress to care in an incubator
<b>Search Details</b>	
Sources	CENTRAL, CINAHL, MEDLINE, Oxford Database of Perinatal Trials. Hand searching, asking experts, reference lists were searched.
Range (years) of included studies	1989-2004
No. of studies	5
Types of studies included	Randomised controlled trials (including one cross-over design)
Country of origin of included studies	Turkey and Ethiopia. Plus three unspecified developed countries.
<b>Appraisal</b>	
Appraisal instruments used	Cochrane ROB tool
Appraisal rating	Studies were graded as low risk of bias for all domains except Blinding (performance bias and detection bias)
<b>Analysis</b>	
Method of analysis	Meta-analysis
Outcome assessed	Primary Outcomes: body temperature (episodes of cold stress (<36 degrees C), episodes of hyperthermia (>37.5 degrees C)) and weight gain. Secondary Outcomes: oxygen consumption, length of stay, breastfeeding rate at discharge, episodes of nosocomial sepsis, maternal perceptions of infant conditions, maternal stress and anxiety, nursing perceptions of ability to provide care, cost and death
Results/findings	<p>Cot nursing (any type) vs incubator</p> <ul style="list-style-type: none"> <li>• Body temperature. All trials reported on this but one excluded from meta-analysis. No difference in mean body temperature (mean difference [MD]: 0.02, CI: -0.20-0.07) but there was high levels of heterogeneity. Only one trial examined episodes of cold stress as an outcome and found no significant difference between groups. Only one study reported on hyperthermia and reported no difference between groups.</li> <li>• Weight gain. Three trials reported on this. No significant differences between groups (week one MD 0.19 g/kg/day; 95% CI - 2.39 to 2.77; week two MD 0.91 g/kg/day; 95% CI -0.51 to 2.33; week three MD 0.35 g/kg/day; 95% CI -4.41, 5.11. It should be noted there was statistical heterogeneity identified in week 1.</li> <li>• Oxygen consumption. Only two trials measured this and no significant difference found between the groups (MD -0.17 ml/kg/min; 95% CI -0.47 to 0.13)</li> <li>• Breastfeeding at discharge. Three trials reported on this. Non-significant reduction in number of infants not breastfeeding at discharge in the cot group (typical RR 0.74; 95% CI 0.48 to 1.14)</li> <li>• Nosocomial Sepsis. Two trials reported on this and no significant differences reported between groups in either trial.</li> </ul>

	<ul style="list-style-type: none"> <li>• Maternal stress and anxiety. One trial reported on this and no significant difference.</li> <li>• Death. Four trials reported on this and no significant difference (RR 0.59; 95% CI 0.28 to 1.25).</li> </ul> <p>Cot-nursing with heated water-filled mattress and incubator care</p> <ul style="list-style-type: none"> <li>• Body temperature. Four trials reported on mean body temperature and results the same as the overall comparison. One trial reported that was no significant difference in cold stress hypothermia but there was a significant increase in hyperthermia in the cot nursing group (RR 1.48; 95% CI 1.04 to 2.09)</li> <li>• Weight gain. Three trials reported on this. No significant difference. Mean difference (MD) and 95% CI for weeks one, two and three were 1.30 g/kg/day (-1.48 to 4.08), 0.90 g/kg/day (-0.57 to 2.37) and 1.21g/kg/day (-3.77 to 6.18) respectively.</li> <li>• For the secondary outcome measures of oxygen consumption, breast feeding at hospital discharge, episodes of nosocomial sepsis, maternal perceptions of infant's condition and maternal stress and anxiety the same trials were included as for the overall comparison</li> <li>• Death. Three trials reported on this. No significant difference (typical RR 0.63; 95% CI 0.30 to 1.34).</li> </ul> <p>Cot-nursing using warming of the nursery vs incubator care</p> <ul style="list-style-type: none"> <li>• Weight gain. Only one trial looked at this. At week 1 infants in cots had significantly less weight gain but this was not significant in weeks 2 or 3.</li> </ul>
Significance/direction	No significant difference in temperature control and weight gain when a heated water filled mattress was used instead of an incubator. But when warming of the nursery was used weight gain was significantly smaller in the cot group.
Comments	High quality review but small number of studies. More studies necessary on all outcome measures.

<b>Study Details</b>	2813
Author/year	Johnston et al. 2014
Review theme	Methods for Improving Family Centred Care
Objectives	<p>The primary objectives were to determine the effect of SSC alone on pain from medical or nursing procedures in neonates undergoing painful procedures compared to no intervention, sucrose or other analgesics, or additions to simple SSC such as rocking; and the effects of the amount of SSC (duration in minutes) and the method of administration (who provided the SSC, positioning of caregiver and neonate pair).</p> <p>The secondary objectives were to determine the incidence of untoward effects of SSC and to compare the SSC effect in different postmenstrual age subgroups of infants.</p>



Participants (characteristics/number)	Term and preterm infants receiving SSC for painful procedures conducted by doctors, nurses, or other healthcare professionals (n=1594)
Setting/Context	NICU
Description of Interventions/ phenomena of interest	Skin to skin care for the prevention of procedural pain
<b>Search Details</b>	
Sources	CENTRAL, MEDLINE, Evidence-Based Medicine Reviews, EMBASE, WOS, LILACS, SCIELO, PsycInfo, AMED, issertation-Abstracts International
Range (years) of included studies	2000-2013
No. of studies	19
Types of studies included	Randomised or quasi-randomised controlled trials.
Country of origin of included studies	Not stated
<b>Appraisal</b>	
Appraisal instruments used	Cochrane ROB tool.
Appraisal rating	Just over half of studies were low risk in the random sequence generation domain and the rest were judged as unclear. Just over half of studies were unclear risk of bias in the allocation concealment domain and the rest were low risk. 25% were low risk in the blinding domain, 20% high risk and the remaining unclear risk. Just over ¾ were low risk in the incomplete data domain and the remaining were unclear risk 80% were low risk in the selective reporting domain, 15% unclear risk and 5% high risk. 2/3 were low risk of other bias and the rest were either unclear or high risk of bias.
<b>Analysis</b>	
Method of analysis	Meta-analysis
Outcome assessed	Primary outcomes: behavioural indicators, physiological indicators, hormonal indicators, validated composite pain scores Secondary outcomes: response of SSC provider (including self-report, cortisol and physiological indicators) and adverse events including bradycardia, desaturation and apnoea.
Results/findings	Skin to skin care vs incubator control. <ul style="list-style-type: none"> <li>• Heart rate response. Four studies included in meta-analysis. Non-significant MD of 0.35 (95% CI -6.01 to 6.71)</li> <li>• Heart rate recovery. Four studies included in meta-analysis. Non-significant MD of -3.73 (95% CI -8.86 to 1.39)</li> <li>• Heart variability. Reported in two studies so no meta-analysis. Neither study reported a significant effect.</li> <li>• Oxygen saturation during procedure. Three studies but heterogeneity so not combined. Two studies favoured SSC.</li> <li>• Oxygen saturation after procedure. Three studies but heterogeneity so not combined. One study favoured SSC.</li> </ul>

	<ul style="list-style-type: none"> <li>• Change on oxygen saturation. Only one study but no significant difference.</li> <li>• Serum cortisol. Only one study. Significantly higher cortisol in 80 min SSC group but was significantly lower in the 30min SSC group.</li> <li>• Salivary cortisol. Only one study. Significantly higher cortisol in 80 min SSC group but was significantly lower in the 30min SSC group.</li> <li>• Premature Infant Pain Profile (PIPP) at 30 seconds. Four studies in MA. Significant effect in favour of SSC (MD -3.21, 95% CI -3.94 to -2.48)</li> <li>• PIPP at 60 seconds. Three studies in MA. Significant difference in favour of SSC (MD -1.85, 95% CI -3.03 to -0.68).</li> <li>• PIPP at 60 seconds. Three studies in MA. No significant difference in favour of SSC (MD 0.04, 95% CI -1.14 to 1.23).</li> <li>• PIPP at end of procedure. One study which favoured SSC. Significance value not stated.</li> <li>• Neonatal facial coding system (NFCS) during procedure. Two studies and no MA. One study had a significant difference in favour of SSC the other did not.</li> <li>• NFCS at recovery. Two studies and no MA. Both studies favoured SSC.</li> <li>• Duration of crying. Two studies in MA. No significant difference (MD -0.93, 95% CI -2.28 to 0.42)</li> <li>• Neonatal Pain Score. Three studies not combined in MA due to heterogeneity. All three favoured SSC.</li> <li>• Sleep and wake state. Four studies not combined in MA due to heterogeneity. No differences in sleep and wake state at the time of the invasive procedure.</li> </ul> <p>Effectiveness of SSC with different providers.</p> <ul style="list-style-type: none"> <li>• Two studies reported on this but no significant differences in heart rate recovery or PIPP scores.</li> </ul> <p>Duration of SSC</p> <ul style="list-style-type: none"> <li>• Two studies reported on this and seemed to favour 30 min of SSC over shorter or longer doses.</li> </ul> <p>No adverse effects reported.</p>
Significance/direction	Studies comparing skin-to-skin care to standard care, favoured skin-to-skin care or were non-significant.
<b>Comments</b>	High quality review but only a small number of data sets pooled in each analysis (maximum 4) and for many outcomes it was not possible to calculate a pooled effect size due to heterogeneity.

<b>Study Details</b>	2821
Author/year	Benzies et al. 2013
Review theme	Methods for Improving Family Centred Care
Objectives	To categorize the key components of early intervention programs and determine the direct effects of components on parents, as well as their preterm infants
Participants (characteristics/number)	Preterm infants <37 weeks and/or LBW (<2500g) (n=3431)

Setting/Context	
Description of Interventions/ phenomena of interest	Early intervention defined as 'prevention-focused programs occurring soon after birth when the infant's brain is plastic'. Interventions in this review aim to support parents to improve the quality of the infant's environment. Can take the form of psychosocial support for parents, educational intervention or therapeutic developmental support for the child delivered by the parent.
<b>Search Details</b>	
Sources	MEDLINE, EMBASE, CINAHL, ERIC, and Cochrane Database of Systematic Reviews
Range (years) of included studies	1990-2011
No. of studies	18 in qualitative synthesis and 11 in meta-analysis
Types of studies included	RCTs
Country of origin of included studies	Australia, England, Germany, Italy, Japan, Netherlands, Norway and the US.
<b>Appraisal</b>	
Appraisal instruments used	Cochrane Risk of Bias tool
Appraisal rating	low risk of bias related to random sequence generation in 70% of the trials. Only four studies adequately described the concealment of treatment allocation High refusal rate in three studies Attrition was high in three studies
<b>Analysis</b>	
Method of analysis	Qualitative synthesis and meta-analysis
Outcome assessed	Maternal stress, anxiety, depressive symptoms, self-efficacy, sensitivity/responsiveness in interactions
Results/findings	<ul style="list-style-type: none"> <li>Stress (7 studies). SMD = -0.04 (95% CI: -0.23-0.15). No significant effect favouring intervention.</li> <li>Anxiety (4 studies). SMD = -0.54 (95% CI: -0.95- -0.12).</li> <li>Depressive symptoms. SMD = -0.39 (95% CI: -0.39- -0.20)</li> <li>Self-efficacy (2 studies). SMD = 0.62 (95% CI: 0.03-1.22)</li> <li>Sensitivity/responsiveness (6 studies). SMD = 0.37 (95% CI: -0.02 - 0.76)</li> </ul>
Significance/direction	<ul style="list-style-type: none"> <li>Non-significant effect favouring intervention for stress.</li> <li>Significant effect favouring intervention for anxiety.</li> <li>Significant effect favouring intervention for depressive symptoms.</li> <li>Significant effect favouring intervention for self-efficacy</li> <li>Significant effect favouring intervention for sensitivity/responsiveness</li> </ul>
<b>Comments</b>	High quality review but meta-analysis has high levels of heterogeneity.

## Appendix 3.4 Discharge/Transitional care data extraction tables

<b>Study Details</b>	603
Author/year	Collins et al. 2015
Review theme	Early Discharge
Objectives	To determine the effects of a policy of early discharge of stable preterm infants with home support of gavage feeding compared with a policy of discharge of such infants when they have reached full sucking feeds.
Participants (characteristics/number)	Stable preterm infants and their families (88 infants from 75 families)
Setting/Context	Home versus neonatal care unit
Description of Interventions/ phenomena of interest	Infants were discharged home whilst receiving tube feeding (instead of waiting the suckling reflex to develop prior to discharge). Professional support was given at home to help the baby graduate to full suckling feeds
<b>Search Details</b>	
Sources	CENTRAL, CINAHL, MEDLINE, EMBASE. Standard search strategy of the neonatal group was used.
Range (years) of included studies	No date limit was placed.
No. of studies	1
Types of studies included	Randomised and quasi-randomised trial (note the one included study was quasi-randomised)
Country of origin of included studies	Sweden
<b>Appraisal</b>	
Appraisal instruments used	Cochrane Risk of Bias
Appraisal rating	High risk of bias for three out of four domains
<b>Analysis</b>	
Method of analysis	Descriptive (meta-analysis not possible as only one study)
Outcome assessed	Mean hospital stay, clinical infection, duration and extent of breastfeeding, weight gain, re-admission in first 12 months post-discharge home, mortality, parental satisfaction and anxiety
Results/findings	<ul style="list-style-type: none"> <li>• Mean hospital stay: early discharge infants had a mean hospital stay that was that was 9.3 days shorter (mean difference (MD) - 9.3, 95% confidence interval (CI) -18.49 to -0.11)</li> <li>• Clinical infection: early discharge infants had a lower risk of clinical infections (risk ratio 0.35, 95% CI 0.17 to 0.69).</li> <li>• No significant differences between groups in terms of breastfeeding, weight gain or re-admission in first 12 months post-discharge home, mortality, confidence in handling baby at time of discharge, preparedness to take responsibility for the care of the infant or anxiety</li> </ul>
Significance/direction	<ul style="list-style-type: none"> <li>• Supports intervention in terms of reduced hospital stay and reduced risk of infection</li> </ul>
<b>Comments</b>	High quality Cochrane review but only one study included. No cost-effectiveness analysis undertaken
<b>Study Details</b>	2378
Author/year	Lopez et al. 2012

Review theme	Transition from neonatal care unit to home
Objectives	To identify programs assisting families with preterm infants in the transition from hospital to home life. To assess the effectiveness of ensuring the infant's safety and in meeting the parents' needs To identify the roles and qualifications of professional paediatric home care providers for work with infants and families To identify what methods communication are documented for families to maintain contact with the hospital team after the infant's discharge
Participants (characteristics/number)	Families with preterm (from <32 weeks gestation) or LBW infants (n=3360)
Setting/Context	Transition from neonatal unit to home
Description of Interventions/ phenomena of interest	Transition management of preterm infants that provides support for family caregivers in the step of transitioning from hospital to home life.
<b>Search Details</b>	
Sources	CINAHL, MEDLINE, PubMed
Range (years) of included studies	2004-2011
No. of studies	7
Types of studies included	RCT, retrospective quantitative analysis, non-experimental descriptive study, cluster-randomized controlled trial, program descriptive analysis, qualitative study
Country of origin of included studies	Canada, US, Denmark, UK, Sweden
<b>Appraisal</b>	
Appraisal instruments used	CASP
Appraisal rating	One paper did not pass quality assessment and was excluded but no detail on how this was determined
<b>Analysis</b>	
Method of analysis	Description of included studies
Outcome assessed	N/A
Results/findings	Five components of successful transition programmes were identified: <ul style="list-style-type: none"> <li>• Communication between health care provider and family at home. Videoconferencing, phone contact and a pager allowed parents to stay home but have support from NICU staff.</li> <li>• Home visits. Home visits were associated with breastfeeding, fewer visits to the emergency dept.</li> <li>• Assessment of the infant and home situation. Videoconferencing allowed assessment of the infant. Maternal health, parenting skills and home environment also part of assessment process.</li> <li>• Education, Educational and Support Groups. Educational groups served as support groups provided critical information and guidance to parents.</li> <li>• Role of the Nurse. Nurse involvement was a key element in all transitional programmes and their role included assessment and care of infant in hospital and at home, educating the parents about prematurity, assessing maternal health, providing support for parents, making referral to community resources</li> </ul>
Significance/direction	N/A

<b>Comments</b>	Low quality review. Some examples of transitional care identified but further research needed.
<b>Study Details</b>	1818
Author/year	Miah 2013
Review theme	Transition from neonatal care unit to home
Objectives	To establish if transitional care improves neonatal and maternal health outcomes
Participants (characteristics/number)	Preterm neonates weighing >1.4kg and preterm gestation >33 weeks
Setting/Context	Neonatal transitional care units
Description of Interventions/ phenomena of interest	Transitional care units for preterm and term LBW infants requiring medical management to maintain adequate growth and medical stability.
<b>Search Details</b>	
Sources	Medline, CINAHL, Cochrane Library, EBSCO electronic journals services, health information services, intermid.co.uk, maternity and infant care databases, Science Direct and British midwifery online journals, Google. Hand searches of midwifery and neonatal journals. Reference citations from relevant articles were followed up for further potential studies.
Range (years) of included studies	1995-2011
No. of studies	10
Types of studies included	Observational, audit, descriptive of describing development of transitional care, surveys, literature review. Predominantly grey literature.
Country of origin of included studies	
<b>Appraisal</b>	
Appraisal instruments used	Adapted tool from Egger et al. (2001) and Higgins et al. (2008). Studies graded as strong, moderate, weak or very weak using the CRD quality definition. However, from reading the article the author seems focused on reporting quality and not risk of bias.
Appraisal rating	Very poor = 1 Moderately poor = 1 Moderately high = 4 Very high = 4
<b>Analysis</b>	
Method of analysis	Narrative synthesis
Outcome assessed	Primary outcome: length of stay, model of care, risk of cross infection Secondary outcome: increased potential for breastfeeding, frees resources, family centred care, bonding/attachment, parenting skills, mother as main carer, midwives role
Results/findings	<ul style="list-style-type: none"> <li>Length of stay. 6/10 studies report that transitional care reduces length of stay. Argue that this has cost-effectiveness benefits.</li> <li>Model of Care. The MoC has benefits in terms of reduced risk of infection and increased potential for breastfeeding.</li> </ul>

	<ul style="list-style-type: none"> <li>• Risk of cross-infection. Two studies reported on this and suggest risk of infection decreased in transitional care infants as the mother is the main carer</li> <li>• Increased potential breastfeeding rate. This was supported by four studies.</li> <li>• Frees resources. Five studies report on this and support this although more cost effectiveness analysis is needed</li> <li>• Family-centred care. Six studies report on this and support TCU in promoting this.</li> <li>• Parenting skills. Six studies report on this and support TCU in promoting this.</li> <li>• Bonding/attachment. Seven studies report on this and support TCU in promoting this.</li> <li>• Mother as main carer. Six studies report on this and support TCU in promoting this.</li> <li>• Midwives role. TCU can employ a model of care provided by midwives and neonatal nurses who work as a team to provide a combined care package. As midwives can offer maternal care and breastfeeding and neonatal nurses provide care for the ill infants, the collaboration provides good support.</li> </ul>
Significance/direction	Not reported
<b>Comments</b>	This is a very poor review. The majority of studies are unpublished and descriptive but described as being of high quality. Despite positive effects being reported no effect sizes or measures of significance are detailed. Things such as model of care are described as outcomes, which does not make sense.

## Appendix 3.5 Workforce Configuration

<b>Study Details</b>	2378
Author/year	Sherenian et al. 2013
Review theme	Workforce configuration
Objectives	To determine how nurse-to-patient ratios or nursing workload affects outcomes in the NICU
Participants (characteristics/number)	Infants admitted to NICUs (n=22155)
Setting/Context	NICU
Description of Interventions/ phenomena of interest	Exploration of the relationship between nurse-to-patient ratios or nursing workload and outcomes in NICU patients
<b>Search Details</b>	
Sources	PubMed, Medline, EMBASE
Range (years) of included studies	1990-2010
No. of studies	6
Types of studies included	Observational
Country of origin of included studies	US, UK, Australia and South America
<b>Appraisal</b>	
Appraisal instruments used	STROBE
Appraisal rating	Average of 29 or 32 STROBE criteria (range 27-31). Most studies did not report how they handled missing data or describe efforts to address potential sources of bias in the data. Importantly, no study reported that their tool for collecting and analysing staffing data was valid or reliable.
<b>Analysis</b>	
Method of analysis	Narrative
Outcome assessed	Neonatal mortality
Results/findings	<ul style="list-style-type: none"> <li>3 studies reported low nurse-patient ratio was associated with higher mortality (OR: 1.8, 1.3, 1.5) and one was associated lower mortality (OR 0.2)</li> </ul> Note cut-off for low ratio defined differently in different studies
Significance/direction	Significance not reported
<b>Comments</b>	Adequate review but included studies high risk of bias



Appendix 4. Critical Appraisal

Study identification <i>Include author, title, reference, year of publication</i>	2559. Aagaard and Hall. 2008. Mothers' Experiences of Having a Preterm Infant in the Neonatal Care Unit: A Meta-Synthesis		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	1831 Alves et al. 2013 Parents' views on factors that help or hinder breast milk supply in neonatal care units: systematic review		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear

The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	792 Butt et al. 2013 An integrative review of parent satisfaction with care provided in the neonatal intensive care unit		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes Note no formal tool used and studies at high risk of bias	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	1094 Cleveland, 2008
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	Parenting in the Neonatal Intensive Care Unit		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b>Circle or highlight one option for each question</b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification	603		
<i>Include author, title, reference, year of publication</i>	Collins et al. 2015 Early discharge with home support of gavage feeding for stable preterm infants who have not established full oral feeds (Review)		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b>Circle or highlight one option for each question</b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear

An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear
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Study identification <i>Include author, title, reference, year of publication</i>	976 Lasswell et al. 2010 Perinatal Regionalization for Very Low-Birth-Weight and Very Preterm Infants
Checklist completed by:	Anna Gavine

**SCREENING QUESTIONS**

<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes (but no formal tool used)	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	1041 De Rouck and Les. 2009 Information needs of parents of children admitted to a neonatal intensive care unit A review of the literature (1990–2008)
Checklist completed by:	Anna Gavine

**SCREENING QUESTIONS**

<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>
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The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	1830 Chan et al. 2015 Kangaroo mother care: a systematic review of barriers and enablers		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	2482 Kearvell et al. 2010
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	Getting connected: How nurses can support mother/infant attachment in the neonatal intensive care unit		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b>Circle or highlight one option for each question</b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification	2482		
<i>Include author, title, reference, year of publication</i>	Kearvell et al. 2010 Getting connected: How nurses can support mother/infant attachment in the neonatal intensive care unit		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b>Circle or highlight one option for each question</b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear

An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear
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Study identification <i>Include author, title, reference, year of publication</i>	2378 Lopez et al. 2012 Transition of Premature Infants From Hospital to Home Life
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Checklist completed by:	Anna Gavine
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**SCREENING QUESTIONS**

**In a well-conducted, relevant systematic review:** *Circle or highlight one option for each question*

The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
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The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
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The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
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Study quality is assessed and reported	Yes	No	Unclear
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An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear
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Study identification <i>Include author, title, reference, year of publication</i>	1818 Miah et al. 2013 Does transitional care improve neonatal and maternal health outcomes? A systematic review
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Checklist completed by:	Anna Gavine
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**SCREENING QUESTIONS**

**In a well-conducted, relevant systematic review:** *Circle or highlight one option for each question*

The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
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The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
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The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	1225 Mori et al. 2007 Duration of inter-facility neonatal transport and neonatal mortality: Systematic review and cohort study		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b>Circle or highlight one option for each question</b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	829 Bandyopadhyay et al. 2012 Does Facility-Based Newborn Care Improve Neonatal Outcomes? A Review of Evidence		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b>Circle or highlight one option for each question</b>		



The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	606 Provenzi & Santoro. 2015. The lived experience of fathers of preterm infants in the Neonatal Intensive Care Unit: a systematic review of qualitative studies		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	2512 Obeidat et al. 2009
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	The Parental Experience of Having an Infant in the Newborn Intensive Care Unit		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b>Circle or highlight one option for each question</b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	1816 Rashidian et al. 2014 The effectiveness of regionalization of perinatal care services - a systematic review		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b>Circle or highlight one option for each question</b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	2235 Percecao et al. 2014 Parents' and nurses' perceptions of Nursing care in neonatology – an integrative review		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	641 Rosenstock and van Manen. 2014 Adolescent Parenting in the Neonatal Intensive Care Unit		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear

An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear
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Study identification <i>Include author, title, reference, year of publication</i>	836 Shahheidari & Homer. 2012 Impact of the Design of Neonatal Intensive Care Units on Neonates, Staff, and Families		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	737 Sherenian et al. 2013 Nurse-to-Patient Ratios and Neonatal Outcomes: A Brief Systematic Review		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear

The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification	2214
<i>Include author, title, reference, year of publication</i>	Sissonn et al. 2015 Metaethnographic Synthesis of Fathers' Experiences of the Neonatal Intensive Care Unit Environment During Hospitalization of Their Premature Infants
Checklist completed by:	Anna Gavine

**SCREENING QUESTIONS**

<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification	2795 and 2360
<i>Include author, title, reference, year of publication</i>	Staniszewska et al. 2012 The POPPY Study: Developing a Model of Family-Centred Care for Neonatal Units

	Brett et al. 2011 A systematic mapping review of effective interventions for communicating with, supporting and providing information to parents of preterm infants		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	1466 Swartz 2005 Parenting Preterm Infants: a Meta-Synthesis		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear

Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	2796 Renfrew et al. 2009 Breastfeeding promotion for infants in neonatal units: a systematic review and economic analysis
Checklist completed by:	Anna Gavine

**SCREENING QUESTIONS**

<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	2278 Conde-Agudelo & Diaz-Rossello. Kangaroo mother care to reduce morbidity and mortality in low birthweight infants
Checklist completed by:	Anna Gavine
<b>SCREENING QUESTIONS</b>	
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>

The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	2814 Chang et al. 2015 Specialist teams for neonatal transport to neonatal intensive care units for prevention of morbidity and mortality		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review: <i>Circle or highlight one option for each question</i></b>			
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	2812 Gray & Flenady. 2011
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	Cot-nursing versus incubator care for preterm infants		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b>Circle or highlight one option for each question</b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification	2813		
<i>Include author, title, reference, year of publication</i>	Johnston et al. 2013 Skin-to-skin (Kangaroo Care) with newborns cuts down procedural pain		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b>Circle or highlight one option for each question</b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

Study identification <i>Include author, title, reference, year of publication</i>	2821 Benzies et al. 2013		
Checklist completed by:	Anna Gavine		
<b>SCREENING QUESTIONS</b>			
<b>In a well-conducted, relevant systematic review:</b>	<b><i>Circle or highlight one option for each question</i></b>		
The review addresses an appropriate and clearly focused question that is relevant to the guideline review question	Yes	No	Unclear
The review collects the type of studies you consider relevant to the guideline review question	Yes	No	Unclear
The literature search is sufficiently rigorous to identify all the relevant studies	Yes	No	Unclear
Study quality is assessed and reported	Yes	No	Unclear
An adequate description of the methodology used is included, and the methods used are appropriate to the question	Yes	No	Unclear

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