National Institute for Health and Care Excellence

Final

Specialist neonatal respiratory care for babies born preterm

[G] Evidence reviews for discharge planning

NICE guideline NG124

Evidence reviews

April 2019

Final

These evidence reviews were developed by the National Guideline Alliance, hosted by the Royal College of Obstetricians and Gynaecologists

Disclaimer

The recommendations in this guideline represent the view of NICE, arrived at after careful consideration of the evidence available. When exercising their judgement, professionals are expected to take this guideline fully into account, alongside the individual needs, preferences and values of their patients or service users. The recommendations in this guideline are not mandatory and the guideline does not override the responsibility of healthcare professionals to make decisions appropriate to the circumstances of the individual patient, in consultation with the patient and/or their carer or guardian.

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Contents

Discharging planning

This evidence report contains information on 2 reviews relating to discharge planning.

- Review question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?
- Review question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

Review question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

Introduction

Due to clinical advances in medical technologies there are an increasing number of children being discharged home who are still receiving respiratory support. This may include oxygen therapy or long-term ventilation, delivered either non-invasively via facemask or face shield, or invasively via a tracheostomy. Although discharge home is considered to be in the best interest of the child and their family, discharging a child home on respiratory support is a complex process and often presents a number of challenges.

The review aims to explore factors that professionals agree are important to ensure the safe discharge from hospital of a child requiring respiratory support.

Summary of the protocol

See Table 1 for a summary of the population, intervention/context and outcome characteristics of this review.

Table 1: Summary of the protocol

Population	**Inclusions:** • Professionals in the multidisciplinary team (MDT) caring for preterm babies who require respiratory support **Exclusions:** • Professionals caring for preterm babies with any congenital abnormalities excluding patent ductus arteriosus (PDA) • Professionals caring for preterm babies who are ventilated solely due to neurological disorders • Quantitative studies that do not provide qualitative data i.e. survey data
Intervention/ context	Minimum requirements that professionals caring for preterm babies requiring respiratory support find important in regards to the safe transition of the baby from the neonatal unit to a care setting (i.e. the home or hospice care) where the parents/carers, as opposed to healthcare professionals, are the main caregivers.
Outcomes	Themes will be identified from the literature, but expected themes are: • Access to the MDT, including medical, specialist nursing and therapy teams, and psychological support • Community team involvement • Training or qualifications of the care provider that will be providing care post neonatal unit discharge • Named discharge co-ordinator or key worker, such as named consultant or nurse • Training and completion of competencies of parents • Medication administration • Support to facilitate the confidence of parents • Equipment provision • Care package funded • Suitable discharge destination environment ○ Housing

	○ Electricity • Follow-up care including discharge summaries

MDT: multidisciplinary team; PDA: patent ductus arteriosus

For full details see review protocol in appendix A.

Clinical evidence

A single search was conducted to look for systematic reviews and qualitative studies.

Included studies

Two qualitative studies were included in this review (Helder 2012; Hobbs 2017).

One study (Helder 2012) focused on the perspective of critical care nurses in the neonatal intensive care unit (NICU) and the specialist care nursery (SCN) in the Netherlands and the other (Hobbs 2017) focused on the perspectives of neonatology fellows in the US. The studies collected data by semi-structured interviews and conducted the analysis through thematic analysis.

See the literature search strategy in appendix B and study selection flow chart in appendix C.

Excluded studies

Studies not included in this review with reasons for their exclusions are provided in appendix K.

Summary of qualitative studies included in the evidence review

Table 2 provides a brief summary of the included studies.

Table 2: Summary of included studies

Study and setting	Participants	Methods	Themes
Helder 2012 The Netherlands	**Study participants** n= 18 Three nurses from the NICU and 3 from each SCN were interviewed. **Study babies** n=24 Gestational age, weeks, median (IQR)= 30.7 (26.0-39.4) Birth weight, grams, median (IQR)= 1780 (635-4000) Female, n (%)= 16 (66.7) CRIB score, mean (SD)= 2 (0.5)	**Sampling** Sampling method not reported **Setting** 5 level 2 SCNs in the Netherlands **Data collection** The interview guide was developed from a literature review. Interviews were conducted by pairs of nursing students under supervision from the second author. Interviews were audio-recorded and transcribed verbatim. **Data analysis** Thematic analysis was used.	**Preparing parents for baby's daily care needs** -Mentally **Practical aspects** -Transportation -Home set up

Study and setting	Participants	Methods	Themes
Hobbs 2017 USA	**Study participants** n=10 Female, postgraduate years 4-7 **Study babies** n=10 Gestational age, weeks, median (IQR)= 36.5 (23-40) Male, n (%)= 5 (50) Diagnosis, n (%) Congenital anomaly= 3 (30) Prematurity, n (%)= 2 (20) Discharged with durable medical equipment, n (%)= 4 (40)	**Sampling** Sampling method not reported **Setting** Parents' homes **Data collection** During travel to and from homes, fellows observed the neighbourhood and community resources surrounding the family's neighbourhood and community resources, such as where parents would go to buy food and supplies for the baby. After the home visit, fellows completed semi-structured interviews that were audio-recorded and transcribed. **Data analysis** Thematic analysis was used.	**Preparing parents for the baby's daily care needs** -Mentally -Practically **Practical aspects** -Transportation -Home set up **Interpersonal aspects** -Normalising -Clear and simple communication with parents -Understanding the context

CRIB: clinical risk for babies; IQR: intra-quartile range; NICU: neonatal intensive care unit; SCN: specialist care nursery

See appendix D for full evidence tables and appendix M for the qualitative quotes and excerpts extracted from the studies.

Quality assessment of clinical studies included in the evidence review

See appendix F for full GRADE-CERqual tables.

Economic evidence

No economic evidence on the cost effectiveness of aspects of care that parents and carers value when their baby requires respiratory care was identified by the literature searches of the economic literature undertaken for this guideline.

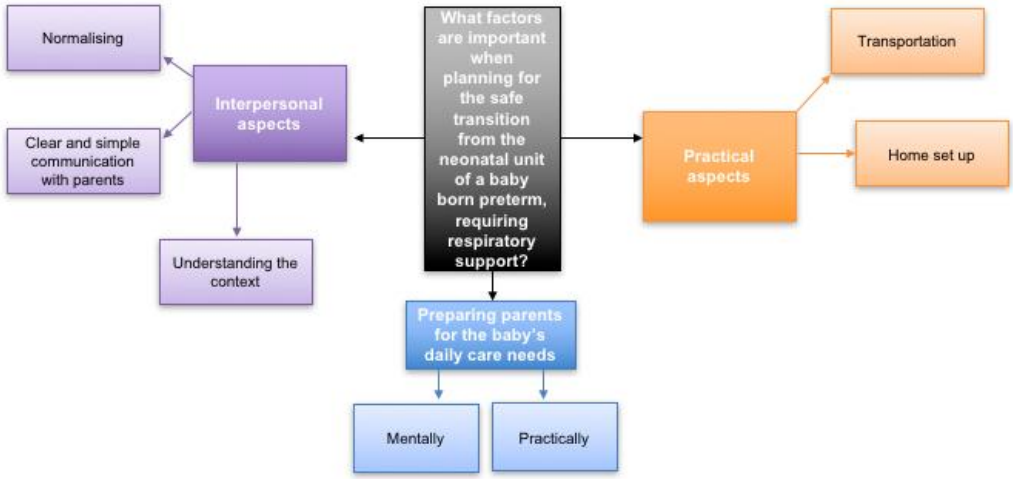
Economic model

No economic modelling was undertaken for this review because the committee agreed that the topic was unsuitable for the economic modelling.

Qualitative evidence statements

Important factors when planning for the safe discharge of a preterm baby requiring respiratory support

Figure 1: Thematic map



Theme 1: Preparing parents for the baby's daily care needs

Mentally

- Very low quality evidence from 2 studies conducted in different countries (the Netherlands, US) among 28 critical care nurses and neonatology fellows responsible for preterm infants requiring respiratory support during discharge from the NICU reported that staff should address parents' fears and anxieties by giving helpful information and encouraging them to express their feelings while participating in the baby's care.

Practically

- Very low quality evidence from 2 studies conducted in different countries (the Netherlands, US) among 28 critical care nurses and neonatology fellows responsible for preterm infants requiring respiratory support during discharge from the NICU reported that it is necessary to prepare parents for the responsibility of their baby's care by involving them in daily care activities in the NICU. Discharge plans should include information on routine newborn care, as well as information specific to their preterm baby's needs, such as calculating battery power or how to attend doctor's appointments with babies on medical technology.

Theme 2: Practical aspects

Transportation

- Very low quality evidence from 2 studies conducted in different countries (the Netherlands, US) 28 among critical care nurses and neonatology fellows responsible for preterm infants requiring respiratory support during discharge from the NICU reported that nurses need to know the time of departure in order to coordinate the transfer and decrease parents' anxiety. It is also important for parents to learn how to travel with their technology-dependent preterm baby to facilitate mobility and attendance at appointments.

Home set up

- Very low quality evidence from 2 studies conducted in different countries (the Netherlands, US) among 28 critical care nurses and neonatology fellows responsible for preterm infants requiring respiratory support during discharge from the NICU reported that parents should be informed of the requirements of the home prior discharge in order to provide them with enough time to make necessary conversions. Homes should be clean and quiet.

Theme 3: Interpersonal aspects

Normalising

- Very low quality evidence from 1 study conducted in the US among 10 neonatology fellows responsible for preterm babies requiring respiratory support during discharge from the NICU reported that parents should be assisted in learning how to normalise daily life, for example, how to run errands or to secure childcare for medically complex babies. Efforts should also be made to ensure that home care routines permit time for parents to sleep and home nursing be made available to provide parents physical and emotional respite.

Clear and simple communication with parents

- Very low quality evidence from 1 study conducted in the US among 10 neonatology fellows responsible for preterm babies requiring respiratory support during discharge from the NICU reported that clear communication throughout the discharge process so that parents can adequately care for the baby. The home nursing team should be identified in advance of the discharge date so as to avoid a rushed and chaotic discharge process. Follow-up appointments should be scheduled with parents and care instructions should avoid medical jargon and acknowledge the new care setting in the home.

Understanding the context

- Very low quality evidence from 1 study conducted in the US among 10 neonatology fellows responsible for preterm babies requiring respiratory support during discharge from the NICU reported that staff from the NICU should account for family dynamics and should consider the role of extended family members during the NICU discharge process. Asking about the social environment is important for staff when creating the discharge plan so that home care routines are appropriate for the family's context.

Economic evidence statements

- No economic evidence on the cost effectiveness of factors that are important when planning for the safe transition from the neonatal unit of a baby born preterm was available.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

This review was conducted from the perspective of healthcare professionals and so outcomes that were most important were factors that healthcare professionals themselves believed were necessary for a safe transition from the neonatal unit of a baby on respiratory support. The committee agreed that the important thematic

outcomes related to preparing parents for the baby's daily care needs, practical aspects (such as administration of medication, use of equipment, suitable housing), the competencies of parents, and interpersonal aspects (such as communication with the family and understanding the family dynamics) trusting relationships with . All of these thematic outcomes were considered useful once the evidence had been appraised. However, some of these themes also related to what parents found useful in the discharge process and so were covered in the recommendations made for review question 7.2, and were not therefore duplicated here. However, it was good that the predefined themes were found to reflect what professionals involved in the multidisciplinary team (MDT) consider important, as the evidence was identified from interviews with professionals themselves.

The committee did not prioritise any of the thematic outcomes.

The quality of the evidence

There was evidence from 2 qualitative studies available for this review (Helder 2012; Hobbs 2017). The studies focused on the perspective of critical care nurses in the neonatal intensive care unit (NICU) and the specialist care nursery (SCN) in the Netherlands and neonatology fellows in the US. The studies collected data by semi-structured interviews and conducted the analysis through thematic analysis.

The quality of evidence was most often downgraded because of methodological limitations affecting the risk of bias, relevance of the findings and the adequacy of the findings.

Methodological limitations affecting the risk of bias were generally attributed to the studies not clearly reporting the sampling method or relationship between the researcher and participants or insufficient evidence to determine whether ethical standards were maintained.

The confidence in the relevance of the evidence was downgraded as a result of some babies not being preterm or having major congenital abnormalities and others not being discharged requiring respiratory support.

The confidence in the adequacy of the evidence was downgraded as a result of data saturation not being reached. This was a result of evidence only being available from a very small number of studies, which meant that themes were under-developed and analysing further data would likely reveal new data and concepts.

The small quantity of evidence and the low quality of the evidence limited the ability of the committee to make recommendations and meant that the committee used their clinical experience and expertise as well in order to develop recommendations. A research recommendation was written as a result of the lack of evidence and low quality of the evidence that was available.

Benefits and harms

The interviews with healthcare professionals identified that, in order to facilitate a safe discharge, parents should be prepared both mentally and practically for discharge – for example by receiving advice and information on caring for their baby at home, using specialist equipment safely, and knowing how to travel with their baby and the equipment. The professionals also reported that the place the baby is going to should be suitable to accommodate the specialist equipment required for the baby's ongoing respiratory needs (for example enough space for equipment, no smokers in the household, enough plug points and a suitable electricity supply). Based on their experience, the committee agreed that sometimes this meant that

alternative locations to home should be considered, such as hospices, relative's homes or other suitable accommodation.

For the interpersonal theme, there was evidence that professionals recognised the value of good communication with parents, providing advice on organisational issues after discharge such as follow-up appointments, and that early involvement and communication with community healthcare teams was important as well. To ensure this the committee recommended, again from their own experience, that a dedicated discharge coordinator could ensure this communication happened.

The committee noted that benefits of the recommendations would include better discharge planning and clearer communication with parents/carers. Better planning could result in early discharge, which would ease pressure on acute beds in the NICU. No harms were identified from the recommendations.

Cost effectiveness and resource use

There was no evidence on the cost effectiveness of strategies for the discharge planning. The committee expressed the view that safe discharge planning leads to appropriate care of preterm babies who require ongoing respiratory support. There may be additional costs associated with facilitating improved communication with parents/carers, regular contact with community healthcare teams, and having a neonatal Discharge Co-Ordinator but this will be outweighed by both the longer term improvements in health outcomes and the potential cost savings to the healthcare system of an early and successful discharge. The committee discussed that even stepping-down the level of care (for example to a hospice, or other less acute setting) minimises the use of acute beds in a neonatal unit and may also result in substantial cost savings to the NHS.

Other factors the committee took into account

The committee discussed inequalities in access to social housing and service provision and the financial strains that having a preterm baby may place on parents/carers. Families who are ineligible for travel subsidies may find it difficult to regularly travel to the NICU before their baby is discharged, which could affect their ability to gain hands-on experience in caring for their baby. Additionally, families who are in unsuitable accommodation, or who cannot afford or obtain financial help to make adaptations to their homes may be unable to accommodate medical equipment or be able to provide a safe environment for their preterm baby. Therefore the committee made a recommendation about discharge to alternative, suitable accommodation, such as a relative's home or hospice, could be an alternative.

The committee agreed that there was a need for the culturally sensitive delivery of information, as it was noted that different cultural groups may have different family structures and housing arrangements.

References

Helder 2012

Helder, O. K., Verweij, J. C. M., Van Staa, A., Transition from neonatal intensive care unit to special care nurseries: Experiences of parents and nurses, Pediatric Critical Care Medicine 2012;13, 305-311

Hobbs 2017

Hobbs, J. E., Tschudy, M. M., Hussey-Gardner, B., Jennings, J. M., Boss, R. D., "I don't know what I was expecting": Home visits by neonatology fellows for infants discharged from the NICU, Birth 2107; 22, 22

Review question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

Introduction

The discharge from hospital of a preterm baby on respiratory support can be very challenging for the parents and carers. These challenges can relate to concerns about the technology and equipment, the availability of ongoing support from healthcare professionals and how to access this, everyday care of a baby on respiratory support, long-term developmental concerns, psychosocial issues, and what to do if problems or emergencies arise.

This review aims to identify what specific information and support is valued by the parents and carers of babies who are discharged from hospital on respiratory support, and the best format and methods to deliver this information and support.

Summary of the protocol

See Table 3 for a summary of the population, intervention/context and outcome characteristics of this review.

Table 3: Summary of the protocol

Population	**Inclusions:** • Parents or carers of preterm babies who require respiratory support • Studies of parents or carers whose baby is born below 37 weeks gestation **Exclusions:** • Parents or carers of preterm babies with any congenital abnormalities excluding patent ductus arteriosus (PDA) • Parents or carers of preterm babies who are ventilated solely due to neurological disorders • Quantitative studies that do not provide qualitative data i.e. survey data
Intervention/context	Type of support, information, and in what format, for parents and carers with regards to preterm babies who are transitioning from the neonatal unit and require ongoing respiratory support.
Outcomes	**Themes** • Access to the multidisciplinary team (MDT), including medical, specialist nursing and therapy teams and community team, continuity of carers, and psychological support for parents/carers and others who share the same household, including siblings • Community team involvement in discharge planning process • Involvement in decision making and care planning for their child • Rooming-in; timing in relation to discharge, experience of stay

	• Experience of training and the support available
	• Experience of different types of training methods and resources available
	• Interventions which enabled/would have enabled parents or carers to feel confident in caring for their baby
	• Equipment provision
	• Care package funded
	• Including experiences of accessing funding package
	• Parent and carer feelings about suitability of the package their child has been awarded
	• Suitable discharge destination environment
	  ○ Housing
	  ○ Electricity
	• Follow-up care in place before discharge with timely provision of relevant documentation such as discharge summaries, paediatric passport, etc.
	• The format in which information is received
	• Equality considerations
	  ○ Accessibility of training and training information (e.g. availability of easy read versions, large print, use of translation or signing services)
	  ○ Advocacy services – availability and use, including presence of an advocate during the training process.
	  ○ Conflict – process and resolution (for example, mediation processes) when parents and carers believe they are able to care for their baby, but professionals disagree. Parental/carer experiences of this.
	Flexibility of training, for example, do parents and carers feel their needs were accommodated? Was it at a time that suited them? Did it last as long as they needed? Were they able to ask questions (and supported to ask questions)?

MDT: multidisciplinary team; PDA: patent ductus arteriosus

For full details see review protocol in appendix A.

Clinical evidence

A single search was conducted to look for systematic reviews and qualitative studies.

Included studies

Seven qualitative studies were included in this review (Burnham 2013; Dellenmark-Blom 2016; Helder 2012; Jackson 2003; Jonsson 2003; Lindberg 2009; Murdoch 2012).

One of these studies focused on the perspective of mothers of preterm babies who are transitioning from the neonatal unit while receiving respiratory support (Murdoch 2012). Six studies focused on the perspective of parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support.

All of the studies collected data via semi-structured interviews. The most common data analysis method was thematic content analysis. Countries in which the studies took place were:

- 2 from Canada (Burnham 2013; Murdoch 2012)
- 1 from the Netherlands (Helder 2012)

- 4 from Sweden (Dellenmark-Blom 2016; Jackson 2003; Jonsson 2003; Lindberg 2009)

See the literature search strategy in appendix B and study selection flow chart in appendix C.

Excluded studies

Studies not included in this review with reasons for their exclusions are provided in appendix K.

Summary of qualitative studies included in the evidence review

Table 4 provides a brief summary of the included studies.

Table 4: Summary of included studies

Study and setting	Participants	Methods	Themes
Burnham 2013 Canada	**Study participants** N=20 Female, n (%)= 16 (80) Age, years, mean (SD)= 35.9 (5.7) **Study babies** N=24 Gestational age, weeks, mean (SD)=31.1 (3.1) Birth weight, grams, mean (SD)=1436.9 (488.1) Mechanical ventilation, n (%)= 6 (33.3) CPAP/HFNC, n (%)= 15 (62.5)	**Sampling** Maximum variance sampling at pre-discharge and post-discharge **Setting** At the hospital in a private room or in the parents' homes **Data collection** Semi-structured interviews were performed in person and lasted one hour. Participants in the pre-discharge group were interviewed prior to going home with the baby and parents in the post-discharge group were interviewed 3-8 weeks after being discharged. Interviews were audio-recorded and transcribed verbatim. **Data analysis** Thematic content analysis was used. Credibility, dependability, confirmability and transferability were assessed to ensure the trustworthiness of the study data.	**Information needs** **Preparation** -How to prepare the home -Hands-on experience in the NICU **Routine care** -Physiological needs -How to tell if baby is doing well -What to do if something goes wrong -Medical information specific to baby's condition **Follow up** **Format** -Timing -Resource -Personnel **Support needs** **NICU staff** -Being able to contact about questions -Self care -Feeling ready -Trust and security

Study and setting	Participants	Methods	Themes
Dellenmark-Blom 2014 Sweden	**Study participants** N=22 Mother, n (%)= 15 (68.2) First time parent, n (%)= 18 (81.8) **Study babies** N=18 Male sex, n (%)= 9 (50) Gestational age, weeks, median (IQR)= 33.5 (25-37) Birth weight, grams, median (IQR)= 1947.5 (870-3200) Medical treatment in the NICU, n (%) Mechanical ventilation= 2 (11.1) Nasal CPAP= 5 (27.8)	**Sampling** Purposive sampling to ensure variability amongst participants **Setting** Parents' homes **Data collection** Open-ended interviews were audio-recorded and transcribed verbatim. Interviews were 26-52 minutes and were started with similar questions aimed to probe the parents to go in depth in their experiences. **Data analysis** Thematic content analysis was used. Meanings were discussed until the researchers agreed. Validity was strengthened through discussions among the researchers about the relationship between parts and the whole of the text.	**Information needs** **Routine care** -How to tell if baby is doing well **Support needs** **NICU staff support** -Being able to contact about questions -Building confidence -Trust and security
Helder 2012 the Netherlands	**Study participants** N= 28 Mothers, n (%)= 21 (75) Non-Dutch ethnic background, n (%)= 7 (25) Mother's age, years, mean (SD)= 31.2 (4.6) **Study babies** N=24 Gestational age, weeks, median (IQR)= 30.7 (26.0-39.4) Birth weight, grams, median (IQR)= 1780 (635-4000) Female, n (%)= 16 (66.7) CRIB score, mean (SD)= 2 (0.5)	**Sampling** Sampling method not reported **Setting** 5 level 2 SCNs in the Netherlands **Data collection** The interview guide was developed from a literature review. Interviews were conducted by pairs of nursing students under supervision from the second author. Interviews were audio-recorded and transcribed verbatim. **Data analysis** Thematic content analysis was used.	**Information needs** **Preparation** -Transportation from NICU **Support needs** **NICU staff support** -Trust and security
Jackson 2003	**Study participants**	**Sampling** Not reported	**Information needs**

Study and setting	Participants	Methods	Themes
Sweden	N=14 Mothers, n (%)= 7 (50) Mother's age, years, median (IQR)= 32.5 (28-37) Father's age, years, median (IQR)= 32.5 (31-39) **Study babies** N=8 Male, n (%)= 5 (62.5) Birth weight, grams, median (IQR)= 1467.5 (660-2385) Gestational age, weeks, median (IQR)= 30 (25-34)	**Setting** Interviews 1 and 2 took place in the NICU, interviews 3 and 4 took place in the parents' homes **Data collection** The majority of interviews were conducted with mothers and fathers together. Interviews lasted 45-90 minutes and were audio-recorded and transcribed verbatim. Interviews took place at during different time points in the baby's development - 1-2 weeks after birth; at the time of discharge from the NICU; when the baby was 6 months old; and when the baby was 18 months old. **Data analysis** Thematic content analysis was used. The syntheses were validated by the second author and discrepancies were discussed until agreement was reached.	**Preparation** -Hands-on experience in the NICU **Support needs** NICU staff -Feeling ready -Trust and security **Familial** **Other parents**
Jonsson 2003 Sweden	**Study participants** N=23 Age, n (%) < 30= 11 (47.8) 31-35= 7 (30.4) > 36= 5 (21.7) Female, n (%)= 17 (73.9) **Study babies** Not reported	**Sampling** Strategic variance sampling to select participants with varying ages, gender and profession **Setting** Parents' homes or the hospital **Data collection** Interviews were audio-recorded and transcribed verbatim and lasted 30-60 minutes. The interview questions were developed by the study authors and were piloted on 2 participants. **Data analysis** Thematic content analysis was used. Data saturation was reached after 16 interviews.	**Information needs** **Format** -Personnel **Support needs** NICU staff -Being able to contact about questions **Familial**
Lindberg 2009 Sweden	**Study participants** N=20 Mothers, n (%)= 10 (50) Mother's age, years, median (IQR)= 33.5 (28-39)	**Sampling** Purposive sampling **Setting** In the NICU or over the phone **Data collection**	**Support needs** **NICU staff** -Being able to contact about questions -Feeling ready -Trust and security

Study and setting	Participants	Methods	Themes
	Father's age, years, median (IQR)= 37.5 (29-44) **Study babies** N=10 Gestational age, weeks, range= 24-33 Gestational age at discharge, range= 34-39	Data were collected from interviews and notes. The parents were interviewed together. The parents were encouraged to talk freely about their own experiences on the use of the video conferencing. Interviews lasted 30-60 minutes, were audio recorded and were transcribed verbatim. **Data analysis** Thematic content analysis was used.	
Murdoch 2012 Canada	**Study participants** N=9 Mothers, n= 9 Age, years, median (IQR)= 34 (27-42) First pregnancy, n (%)= 6 (66%) **Study babies** N=10 (1 set of twins) Male, n (%)= 6 (60) Gestational age, weeks, median (IQR)= 31 (24-42) Diagnoses, n (%) Preterm= 8 (80) Chronic lung disease= 4 (40) Patent ductus arteriosus= 4 (40) Respiratory distress syndrome= 2 (20)	**Sampling** Opportunistic sampling of members who participated in a larger RCT **Setting** Parents' homes or over the phone **Data collection** Interviews were audio-recorded. Interviewers used an interview guide that was developed from previous studies. Data was collected until thematic saturation was reached. **Data analysis** Thematic content analysis was used. Credibility, transferability, dependability and confirmability were achieved through various methods- a reflective diary, audio-recorder, auditing transcripts, and validation of results by the second author.	**Information needs** **Routine care** -How to tell if the baby is doing well Medical information specific to the baby's condition **Format** -Resource **Support needs** NICU staff -Being able to contact about questions -Building confidence **Familial**

CPAP: continuous positive airway pressure; HFNC: high flow nasal cannula; IQR: intra-quartile range; NICU: neonatal intensive care unit; SCN: specialist care nursery; SD: standard deviation

See appendix D for full evidence tables and appendix M for the qualitative quotes and excerpts extracted from the studies.

Quality assessment of clinical studies included in the evidence review

See appendix F for full GRADE-CERqual tables.

Economic evidence

No economic evidence on the cost effectiveness of aspects of care that parents and carers value when their baby requires respiratory care was identified by the literature searches of the economic literature undertaken for this guideline.

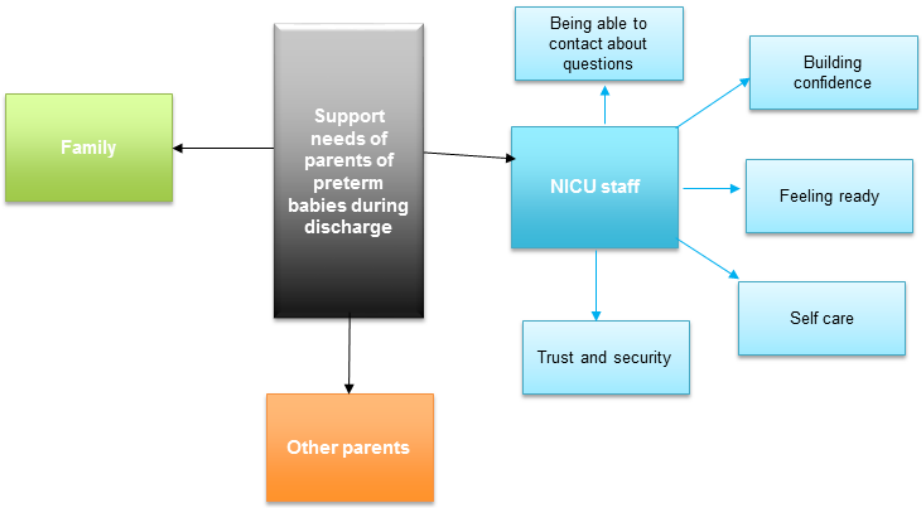
Economic model

No economic modelling was undertaken for this review because the committee agreed that other topics were higher priorities for economic evaluation.

Qualitative evidence statements

Support needs of parents of preterm babies during discharge

Figure 2: Thematic map



Theme 1: NICU staff support

Being able to contact about questions

- Very low quality evidence from 5 studies conducted in different countries (Canada; Sweden) among mothers and parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that having access to NICU staff, preferably those who cared for the baby, to ask questions or discuss concerns improved feelings of support and decreased feelings of abandonment.

Building confidence

- Low quality evidence from 2 studies conducted in different countries (Canada; Sweden) among mothers and parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that NICU staff who provided confirmation and reassurance of the baby's health helped to build mothers' confidence in their caretaking abilities.

Feeling ready

- High quality evidence from 3 studies conducted in different countries (Canada; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that receiving positive feedback from NICU staff and participating in the decisions about the discharge enabled parents to feel ready.

Self care

- Moderate quality evidence from 1 study conducted in Canada among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that NICU staff could remind them about the risk of postpartum depression and provide resources to provide more support.

Trust and security

- Low quality evidence from 5 studies conducted in different countries (Canada; the Netherlands; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that remaining in contact with the NICU post-discharge helped them to feel secure. Having nurses who took the time to discuss questions and concerns while the baby was still in the NICU helped the parents to build a sense of trust and feel secure knowing that they could contact staff later on.

Theme 2: Family

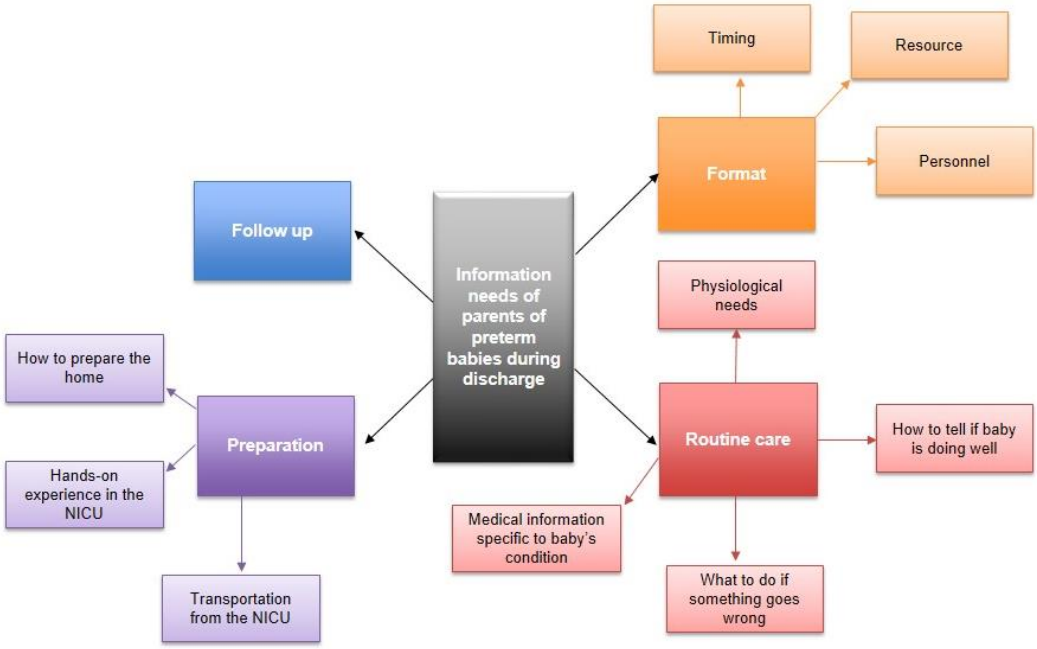
- Very low quality evidence from 3 studies conducted in different countries (Canada; Sweden) among mothers and parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that receiving support from parents or siblings helped mothers to become confident in their caretaking abilities and to distribute the burden of caretaking and household tasks. Additionally, fathers described feeling guilty when they struggled to balance work and family life and wished that they could provide more support for the mothers.

Theme 3: Other parents

- Moderate quality evidence from 1 study conducted in Sweden among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that mothers wanted to be in contact with other mothers of preterm babies whom they had met through parent education sessions organised by the NICU.

Information needs of parents of preterm babies during discharge

Figure 3: Thematic map



Theme 1: Preparation

How to prepare the home

- Moderate quality evidence from 1 study conducted in Canada among parents of preterm babies who are transitioning from neonatal unit while receiving respiratory support reported that parents would have liked a clear set of instructions about the specialised materials that needed to be bought ahead of time, such as thermometers, scales, and respiratory monitors, as well as changes that needed to be made to the home to accommodate equipment. Furthermore, safety instructions, such as limiting the number of visitors to the home should be communicated prior to discharge.

Hands-on experience in the NICU

- Moderate quality evidence from 2 studies conducted in different countries (Canada; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that having the opportunity to care for the baby in a safe environment with the supervision of nurses and staying overnight in the NICU gave them an idea for what life would be like post-discharge and feel ready to take on the caregiving responsibilities.

Transportation from the NICU

- Very low quality evidence from 1 study conducted in the Netherlands among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that parents wanted a consistent policy on whether they could join their baby in the ambulance during transfer from the NICU.

Theme 2: Routine care

How to tell if the baby is doing well

- Moderate quality evidence from 3 studies conducted in different countries (Canada; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that learning about their baby's physiological needs, such as breathing patterns, recognising signs of illness was important for parents to feel prepared for discharge.

What to do if something goes wrong

- Moderate quality evidence from 1 study conducted in Canada among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that parents wanted to know how to handle emergencies, for example if the baby stopped breathing. Courses such as infant cardiopulmonary resuscitation would enable parents to feel better equipped.

Medical information specific to the baby's condition

- Low quality evidence from 2 studies conducted in Canada among mothers and parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that parents wanted information specific to their baby's health condition and about how to perform medical procedures at home.

Physiological needs

- Low quality evidence from 1 study conducted in Canada among parents of preterm babies who are transitioning from neonatal unit while receiving respiratory support reported that parents wanted to know how to adjust routines from the NICU to use in the home. Knowing how to switch to on-demand feeding, how to know when volumes of feeding should be increased, and changes in breastfeeding patterns was important. Additionally, parents wanted to know how to position and swaddle babies when sleeping and what temperature the baby should be at.

Follow up

- Moderate quality evidence from 1 study conducted in Canada among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that having a list of paediatricians to contact post-discharge, how to make follow-up appointments, if babies might experience developmental delays, and immunisations their child required.

Theme 3: Format

Timing

- Low quality evidence from 1 study conducted in Canada among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that preparation should begin on admission with the opportunity to follow up and ask questions throughout the baby's stay in the NICU. However, some noted that parents might not be able to absorb information if it is given too soon after admission.

Resources

- Low quality evidence from 3 studies conducted in different countries (Canada; the Netherlands; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that regardless

of format, resources should be up to date. Pamphlets on basic care at home, nurse-led group support and information sessions, online resources (links to websites or NICU parent networks), and books were mentioned as ideal ways to receive information.

Personnel

- Low quality evidence from 2 studies conducted in different countries (Canada; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that parents preferred learning how to care for their baby from the nurse, but wished to speak with physicians about the baby's health status.

Economic evidence statements

- No economic evidence on the cost effectiveness of the support and information arrangements for the needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving respiratory support was available.

The committee's discussion of the evidence

Interpreting the evidence

The outcomes that matter most

The committee agreed that it was important to meet the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support, and identified that this would need to cover themes including access to the multidisciplinary team for information, involvement in decision-making relating to the discharge process, training and support to learn to care for their baby, equipment, advice about their accommodation requirements to allow for use of their baby's specialist respiratory equipment, follow-up, and access to psychological support. All of these thematic outcomes were considered useful once the evidence had been appraised, and the evidence covered these themes, and additional themes relating to transportation (of their baby and any associated equipment), how to tell if their baby was ill, and what to do if something went wrong.

Together, these thematic outcomes reflect what support and information parents of preterm babies need when transitioning from the neonatal unit while receiving ongoing respiratory support because evidence came from interviews with parents themselves.

The committee did not prioritise any of the thematic outcomes.

The quality of the evidence

The quality of the evidence ranged from very low to high. The quality of evidence was most often downgraded because of methodological limitations affecting the risk of bias, relevance of the findings, coherence of the findings and the adequacy of the findings.

Methodological limitations affecting the risk of bias were attributable to studies not critically reflecting on the researchers' roles in the research, not describing the sampling method, or not discussing methods to ensure credibility, such as

triangulation or participant validation. Additionally, one study did not provide sufficient data to support the findings (Jonsson 2003).

The confidence in the relevance of the findings was downgraded because a portion of the babies were born full-term, had a congenital malformation, or did not require respiratory support.

The confidence in the coherence of the findings was downgraded in one instance as a result of a study reporting conflicting evidence.

The confidence of the adequacy of the evidence was downgraded in some instances as a result of data saturation not being reached. In these instances, the themes were under-developed and analysing further data would likely reveal new data and concepts.

The committee did not think that a research recommendation was a priority due to the strength and quantity of the evidence.

Benefits and harms

The interviews with parents identified that parents liked to be able to ask questions of staff while their baby was still receiving care in the neonatal unit in order to build their confidence to care for their baby and trusting relationships with the staff. After discharge, parents valued being able to contact members of staff to ask questions about the care of their baby, and found it particularly helpful to be able to contact staff who had actually cared for their baby. It was also useful for parents to help them feel ready for the discharge by building their confidence, enabling them to participate in decisions about the discharge planning and to gain hands-on experience caring for their baby in a safe environment with support from the nurses. This included caring for their baby overnight before discharge. The parents also stated that advice about self-care was important, and should include support for postpartum depression. It was also felt by the parents to be important that other members of the family (partners, siblings) received support too, and they wanted to be able to contact other parents of preterm babies for advice.

In terms of information, the parents wished to receive advice about how to prepare their home, including the equipment needed, whether any changes needed to be made to the home, and how to make the home safe for the baby, including issues such as whether visitors should be restricted. They also wanted information on how to transport their baby (especially with equipment), how to tell if their baby was ill, and what to do if something went wrong. In order to care for their babies at home, parents wanted information on how to meet their baby's physiological needs (for example altering the amount of feeds, positioning, adjusting routines, or carrying out simple medical procedures). Parents wanted to be given follow-up information – including who they could contact, how to make follow-up appointments, immunisations and any potential developmental issues.

The parents wanted information to be provided throughout their baby's stay on the NICU, as well as after discharge. Up to date information including pamphlets, support groups, on-line resources and books were appreciated in conjunction with receiving information directly from nurses and other NICU staff.

The committee agreed that the benefits of the recommendations would include a better and more streamlined parent/carer experience throughout the discharge process, as well as safer environments for babies when discharged home. No harms were identified.

Cost effectiveness and resource use

The committee expressed the view that providing care in line with the recommendations would not incur significant extra resource implications.

The cost of providing additional constructive and supportive feedback, information about the risks to mental health, facilitating access to support groups, providing support and information to parents and carers before discharge, and any required training of healthcare professionals would be small.

The recommendations have the potential to improve the support provided to parents and carers, lead to better communication with the family and carers and as a result may lead to more appropriate and safer discharge of a baby on oxygen or assisted ventilation and potentially lead to improved health outcomes. If earlier discharge can be facilitated this may also lead to overall cost savings to the healthcare system.

Other factors the committee took into account

The committee discussed inequalities in access to social housing and service provision and the financial strains that having a preterm baby may place on parents/carers. Families who are ineligible for travel subsidies may find it difficult to regularly travel to the NICU before their baby is discharged, which could affect their ability to gain hands-on experience in daily care needs. Additionally, families who are in unsuitable accommodation, or who cannot afford or obtain financial help to make adaptations to their homes may be unable to accommodate medical equipment or be able to provide a safe environment for their preterm baby. The committee did recognise this and included in their recommendations that babies could be discharged to alternative suitable accommodation if the parents' home was not suitable.

The committee agreed that support and information should be provided in an accessible format – for example in different languages. Parents with low-literacy may struggle to access written information, and these parents/carers may need information in alternative formats.

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Burnham 2013

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Appendices

Appendix A – Review protocols

Review protocol for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

Field (based on PRISMA-P	Content
Review question in SCOPE	What should be included in a discharge plan to facilitate the safe discharge of a baby on oxygen or assisted ventilation?
Review question in guideline	What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?
Type of review question	Qualitative
Objective of the review	To determine what minimum requirements are important from the professional's perspective in order to facilitate the safe transition of a preterm baby on respiratory support
Eligibility criteria – population/disease/condition/issue/domain	Inclusions: • Professionals in the multidisciplinary team (MDT) caring for preterm babies who require respiratory support Exclusions: • Professionals caring for preterm babies with any congenital abnormalities excluding PDA • Professionals caring for preterm babies who are ventilated solely due to neurological disorders • Studies where >2/3 of preterm babies receive respiratory support will be included in the review • Quantitative studies that do not provide qualitative data i.e. survey data
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	Context Minimum requirements that professionals caring for preterm babies requiring respiratory support find important in regards to the safe transition of the baby from the neonatal unit to a care setting (i.e. the home or hospice

Field (based on PRISMA-P	Content
	care) where the parents/carers, as opposed to healthcare professionals, are the main caregivers.
Eligibility criteria – comparator(s)/control or reference (gold) standard	N/A
Outcomes and prioritisation	**Qualitative Themes** Themes will be identified from the literature, but expected themes are: • Access to the MDT, including medical, specialist nursing and therapy teams, and psychological support • Community team involvement • Training or qualifications of the care provider that will be providing care post neonatal unit discharge • Named discharge co-ordinator or key worker, such as named consultant or nurse • Training and completion of competencies of parents • Medication administration • Support to facilitate the confidence of parents • Equipment provision • Care package funded • Suitable discharge destination environment • Housing • Electricity • Follow Up Care including discharge summaries
Eligibility criteria – study design	Qualitative designs: Ethnography, grounded theory, phenomenological, narrative Quantitative designs: Descriptive (from which only qualitative data will be extracted)
Other inclusion exclusion criteria	Inclusion: • English language • Developed countries with a neonatal care system similar to the UK (e.g. OECD countries)

Field (based on PRISMA-P	Content
	• Studies conducted post 2000
Proposed sensitivity/sub-group analysis, or meta-regression	N/A
Selection process – duplicate screening/selection/analysis	Sifting, data extraction, appraisal of methodological quality and GRADE-CERQual assessment will be performed by the systematic reviewer. Resolution of any disputes will be with the senior systematic reviewer and the Topic Advisor. Quality control will be performed by the senior systematic reviewer. Dual sifting and data extraction will not be undertaken for this question.
Data management (software)	Microsoft Excel will be used to organise data into themes NGA STAR software will be used for study sifting, data extraction, recording quality assessment using checklists and generating bibliographies/citations.
Information sources – databases and dates	Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsycINFO, CINAHL Limits (e.g. date, study design): • Apply standard animal/non-English language exclusion • Dates: from 2000 Studies conducted post 2000 will be considered for this review question, as the GC felt that significant advances have occurred in discharge planning policy and management since this time period and outcomes for preterm babies prior to 2000 are not the same as post 2000.
Identify if an update	Not an update
Author contacts	Developer: NGA
Highlight if amendment to previous protocol	N/A
Search strategy	For details please see appendix B
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix D (clinical evidence tables) or H (economic evidence tables).
Data items – define all variables to be collected	For details please see evidence tables in appendix D (clinical evidence tables) or H (economic evidence tables).

Field (based on PRISMA-P	Content
Methods for assessing bias at outcome/study level	The methodological quality of each study will be assessed using the Cochrane checklist for evaluating the quality of qualitative research
Criteria for quantitative synthesis (where suitable)	N/A
Methods for analysis – combining studies and exploring (in)consistency	Appraisal of methodological quality: The quality of the evidence for a theme (i.e. across studies) will be assessed using GRADE-CERQual, a process like GRADE that is adapted for qualitative information Synthesis of data: Thematic content analysis will be used to synthesise the qualitative data. It is a qualitative analytic method that identifies and reports recurrent themes. Thematic analysis is used in qualitative research to focus on examining themes within data and goes beyond counting phrases or words to identifying implicit and explicit ideas within the data. A theme map may also be presented if there is sufficient information identified in the search.
Meta-bias assessment – publication bias, selective reporting bias	N/A
Assessment of confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual.
Rationale/context – Current management	For details please see the introduction to the evidence review in the full guideline.
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by The National Guideline Alliance and chaired by Dr Janet Rennie in line with section 3 of Developing NICE guidelines: the manual. Staff from The National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods chapter of the full guideline.
Sources of funding/support	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Name of sponsor	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists

Field (based on PRISMA-P	Content
Roles of sponsor	NICE funds The National Guideline Alliance to develop guidelines for those working in the NHS, public health, and social care in England
PROSPERO registration number	Not registered

Review protocol for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

Field (based on PRISMA-P	Content
Review question in SCOPE	What should be included in a discharge plan to facilitate the safe discharge of a baby on oxygen or assisted ventilation?
Review question in guideline	What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support? SNRC Review Question 7.1 answers the review question posed in the scope, while Review Question 7.2 has been added in addition to provide greater context to the scope area.
Type of review question	Qualitative
Objective of the review	To determine what support and what information, and in what format, is valued by parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support. Four objectives have been set up: 1. Explore the areas of support that would benefit parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support and assess the means through which parents and carers would like to receive support 2. Explore the areas of support that parents and carers have found acceptable and effective 3. To explore the type of information found valuable by parents and carers of preterm babies who are transitioning from neonatal unit while receiving ongoing respiratory support

Field (based on PRISMA-P	Content
	4. To assess the formats through which parents and carers would like to receive information on transitioning a preterm baby from neonatal unit while receiving ongoing respiratory support
Eligibility criteria – population/disease/condition/issue/domain	Inclusions: • Parents or carers of preterm babies who require respiratory support • Studies of parents or carers whose baby is born below 37 weeks gestation Exclusions: • Parents or carers of preterm babies with any congenital abnormalities excluding PDA • Parents or carers of preterm babies who are ventilated solely due to neurological disorders • Studies where >2/3 of preterm babies receive respiratory support will be included in the review • Quantitative studies that do not provide qualitative data i.e. survey data
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	Context: Type of support, information, and in what format, for parents and carers with regards to preterm babies who are transitioning from the neonatal unit and require ongoing respiratory support.
Eligibility criteria – comparator(s)/control or reference (gold) standard	N/A
Outcomes and prioritisation	Themes • Themes will be identified from the literature, but expected themes are: • Access to the MDT (multidisciplinary team), including medical, specialist nursing and therapy teams and community team, continuity of carers, and psychological support for parents/carers and others who share the same household, including siblings • Community team involvement in discharge planning process • Involvement in decision making and care planning for their child.

Field (based on PRISMA-P	Content
	• Rooming-in; timing in relation to discharge, experience of stay • Experience of training and the support available • Experience of different types of training methods and resources available • Interventions which enabled/would have enabled parents or carers to feel confident in caring for their baby • Equipment provision • Care package funded • Including experiences of accessing funding package • Parent and carer feelings about suitability of the package their child has been awarded • Suitable discharge destination environment • Housing • Electricity • Follow-up care in place before discharge with timely provision of relevant documentation such as discharge summaries, paediatric passport, etc. • The format in which information is received • Equality considerations • Accessibility of training and training information (e.g. availability of easy read versions, large print, use of translation or signing services) • Advocacy services – availability and use, including presence of an advocate during the training process. • Conflict – process and resolution (for example, mediation processes) when parents and carers believe they are able to care for their baby, but professionals disagree. Parental/carer experiences of this. • Flexibility of training, for example, do parents and carers feel their needs were accommodated? Was it at a time that suited them? Did it last as long as they needed? Were they able to ask questions (and supported to ask questions)?

Field (based on PRISMA-P	Content
Eligibility criteria – study design	Qualitative methods: Semi-structured and structured interviews, focus groups, observations Quantitative designs: Surveys (from which only qualitative data will be included)
Other inclusion exclusion criteria	Inclusion: • English language • Developed countries with a neonatal care system similar to the UK (e.g. OECD countries) • Studies conducted post 2000 Studies conducted post 2000 will be considered for this review question, as the GC felt that significant advances have occurred in discharge planning policy and management that would influence the supports available to parents and carers of preterm babies, and thus what they might value, post-2000 that are not the same as prior to 2000.
Proposed sensitivity/sub-group analysis, or meta-regression	N/A
Selection process – duplicate screening/selection/analysis	Sifting, data extraction, appraisal of methodological quality and GRADE-CERQual assessment will be performed by the systematic reviewer. Resolution of any disputes will be with the senior systematic reviewer and the Topic Advisor. Quality control will be performed by the senior systematic reviewer. Dual sifting and data extraction will not be undertaken for this question.
Data management (software)	NGA STAR software will be used for study sifting, data extraction, recording quality assessment using checklists and generating bibliographies/citations. Microsoft Excel will be used to organise data into themes
Information sources – databases and dates	Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase, PsycINFO, CINAHL • Limits (e.g. date, study design): • Apply standard animal/non-English language exclusion • Dates: from 2000

Field (based on PRISMA-P	Content
Identify if an update	Not an update
Author contacts	Developer: NGA
Highlight if amendment to previous protocol	N/A
Search strategy	For details please see appendix B.
Data collection process – forms/duplicate	A standardised evidence table format will be used, and published as appendix D (clinical evidence tables) or H (economic evidence tables).
Data items – define all variables to be collected	For details please see evidence tables in appendix D (clinical evidence tables) or H (economic evidence tables).
Methods for assessing bias at outcome/study level	The methodological quality of each study will be assessed using the Cochrane checklist for evaluating the quality of qualitative research
Criteria for quantitative synthesis (where suitable)	N/A
Methods for analysis – combining studies and exploring (in)consistency	Appraisal of methodological quality: The quality of the evidence for a theme (i.e. across studies) will be assessed using GRADE-CERQual, a process like GRADE that is adapted for qualitative information Synthesis of data: Thematic content analysis will be used to synthesise the qualitative data. It is a qualitative analytic method that identifies and reports recurrent themes. Thematic analysis is used in qualitative research to focus on examining themes within data and goes beyond counting phrases or words to identifying implicit and explicit ideas within the data. A theme map may also be presented if there is sufficient information identified in the search.
Meta-bias assessment – publication bias, selective reporting bias	N/A
Assessment of confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual.
Rationale/context – Current management	For details please see the introduction to the evidence review in the full guideline.

Field (based on PRISMA-P	Content
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by The National Guideline Alliance and chaired by Dr Janet Rennie in line with section 3 of Developing NICE guidelines: the manual. Staff from The National Guideline Alliance undertook systematic literature searches, appraised the evidence, conducted meta-analysis and cost-effectiveness analysis where appropriate, and drafted the guideline in collaboration with the committee. For details please see the methods chapter of the full guideline.
Sources of funding/support	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Name of sponsor	The National Guideline Alliance is funded by NICE and hosted by the Royal College of Obstetricians and Gynaecologists
Roles of sponsor	NICE funds The National Guideline Alliance to develop guidelines for those working in the NHS, public health, and social care in England
PROSPERO registration number	Not registered

Appendix B – Literature search strategies

Literature search strategies for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

Date of initial search: 13/02/18

Database(s): Embase 1980 to 2018 Week 07, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh$).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez
10	neonatal respiratory distress syndrome/ use emez
11	exp Intensive Care, Neonatal/ use ppez
12	newborn intensive care/ use emez
13	exp Intensive Care Units, Neonatal/ use ppez
14	neonatal intensive care unit/ use emez
15	Neonatal Nursing/ use ppez
16	exp newborn nursing/ use emez
17	newborn care/ use emez
18	(special and care and baby and unit*).tw.
19	(SCBU or NICU).tw.
20	or/1-19
21	*hospital discharge/ use emez
22	*Patient Discharge/ use ppez
23	((discharg* or post?discharg*) adj3 (team* or professional* or personnel or specialist* or nurs* or MDT or key worker* or communit*)).tw.
24	((discharg* or post?discharg*) adj3 (plan* or pathway* or pack* or program* or support* or assist* or facilitat* or well?being or co?ordinat* or train* or educat* or visit* or qualification* or competen* or confiden*)).tw.
25	((discharg* or post?discharg*) adj2 (parents or parent or family or families or mother* or maternal or father* or paternal or carer* or caregiver*)).tw.
26	((discharg* or post?discharg*) adj3 (ventilat* or respirat* or breath* or oxygen* or incubat* or "nasal cannula*" or nebuli* or tracheostom*)).tw.
27	((discharg* or post?discharg*) adj3 (environment* or destination* or home or house or housing or electricity or medication* or fund* or equipment or device* or humidifier* or "apn?ea monitor*")).tw.
28	(follow?up adj3 (plan* or pack* or pathway* or program* or support* or co?ordinat* or visit*)).tw.
29	(transition adj3 home).tw.
30	discharge summar*.tw.
31	or/21-30
32	20 and 31
33	limit 32 to english language
34	limit 33 to yr="2000 -Current"
35	Letter/ use ppez
36	letter.pt. or letter/ use emez
37	note.pt.
38	editorial.pt.
39	Editorial/ use ppez
40	News/ use ppez
41	exp Historical Article/ use ppez
42	Anecdotes as Topic/ use ppez
43	Comment/ use ppez
44	Case Report/ use ppez
45	case report/ or case study/ use emez
46	(letter or comment*).ti.
47	or/35-46
48	randomized controlled trial/ use ppez

#	Searches
49	randomized controlled trial/ use emez
50	random*.ti,ab.
51	or/48-50
52	47 not 51
53	animals/ not humans/ use ppez
54	animal/ not human/ use emez
55	nonhuman/ use emez
56	exp Animals, Laboratory/ use ppez
57	exp Animal Experimentation/ use ppez
58	exp Animal Experiment/ use emez
59	exp Experimental Animal/ use emez
60	exp Models, Animal/ use ppez
61	animal model/ use emez
62	exp Rodentia/ use ppez
63	exp Rodent/ use emez
64	(rat or rats or mouse or mice).ti.
65	or/52-64
66	34 not 65
67	remove duplicates from 66

Date of initial search: 13/02/2018

Database(s): AMED (Allied and Complementary Medicine) 1985 to February 2018, Maternity & Infant Care Database (MIDIRS) 1971 to December 2017, PsycINFO 1806 to February Week 1 2018

#	Searches
1	exp infant newborn/ use amed
2	Premature Birth/ use psyh or Neonatal Period/ use psyh or Birth Weight/ use psyh
3	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
4	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
5	(low adj3 birth adj3 weigh$).tw.
6	(LBW or VLBW).tw.
7	Neonatal Intensive Care/ use psyh
8	Intensive Care Neonatal/ use amed
9	(special and care and baby and unit*).tw.
10	(SCBU or NICU).tw.
11	or/1-10
12	Patient Discharge/ use amed
13	Discharge Planning/ use psyh or exp Facility Discharge/ use psyh
14	((discharg* or post?discharg*) adj3 (team* or professional* or personnel or specialist* or nurs* or MDT or key worker* or communit*)).tw.
15	((discharg* or post?discharg*) adj3 (plan* or pathway* or pack* or program* or support* or assist* or facilitat* or well?being or co?ordinat* or train* or educat* or visit* or qualification* or competen* or confiden*)).tw.
16	((discharg* or post?discharg*) adj2 (parents or parent or family or families or mother* or maternal or father* or paternal or carer* or caregiver*)).tw.
17	((discharg* or post?discharg*) adj3 (ventilat* or respirat* or breath* or oxygen* or incubat* or nasal cannula* or nebuli* or tracheostom*)).tw.
18	((discharg* or post?discharg*) adj3 (environment* or destination* or home or house or housing or electricity or medication* or fund* or equipment or device* or humidifier* or apn?ea monitor*)).tw.
19	(follow?up adj3 (plan* or pack* or pathway* or program* or support* or co?ordinat* or visit*)).tw.
20	(transition adj3 home).tw.
21	discharge summar*.tw.
22	or/12-21
23	11 and 22
24	limit 23 to english language [Limit not valid in MWIC; records were retained]
25	limit 24 to yr="2000 -Current"
26	remove duplicates from 25

Date of initial search: 12/02/2018

Database(s): CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature) 1937-current, EBSCO Host

#	Query	Limiters/Expanders
S23	S12 AND S22	Limiters - Publication Year: 2000-2018; English Language; Exclude MEDLINE records

#	Query	Limiters/Expanders
		Search modes - Boolean/Phrase
S22	S13 OR S14 OR S15 OR S16 OR S17 OR S18 OR S19 OR S20 OR S21	Search modes - Boolean/Phrase
S21	TX "discharg* summar*"	Search modes - Boolean/Phrase
S20	TX transition N3 home	Search modes - Boolean/Phrase
S19	TX (("follow up" or follow-up) N2 (plan* or pack* or pathway* or program* or support* or coordinat* or co-ordinat* or visit*))	Search modes - Boolean/Phrase
S18	TX ((discharg* or "post discharg*" or post-discharg*) N3 (environment* or destination* or home or house or housing or electricity or medication* or fund* or equipment or device* or humidifier* or “apnea monitor*” or “apnoea monitor*”))	Search modes - Boolean/Phrase
S17	TX ((discharg* or "post discharg*" or post-discharg*) N3 (ventilat* or respirat* or breath* or oxygen* or incubat* or “nasal cannula*” nebuli* or tracheostom*))	Search modes - Boolean/Phrase
S16	TX ((discharg* or "post discharg*" or post-discharg*) N3 (parents or parent or family or families or mother* or maternal or father* or paternal or carer* or caregiver*))	Search modes - Boolean/Phrase
S15	TX ((discharg* or "post discharg*" or post-discharg*) N3 (plan* or pathway* or pack* or program* or support* or assist* or facilitat* or "well being" or well-being or coordinat* or co-ordinat* or train* or educat* or visit* or qualification* or competen* or confiden*))	Search modes - Boolean/Phrase
S14	TX ((discharg* or "post discharg*" or post-discharg*) N3 (team* or professional* or personnel or specialist* or nurs* or MDT or key worker* or communit*))	Search modes - Boolean/Phrase
S13	(MH "Patient Discharge+")	Search modes - Boolean/Phrase
S12	S7 OR S8 OR S9 OR S10 OR S11	Search modes - Boolean/Phrase
S11	TX (SCBU or NICU)	Search modes - Boolean/Phrase
S10	TX (special and care and baby and unit*)	Search modes - Boolean/Phrase
S9	(MH "Intensive Care Units, Neonatal")	Search modes - Boolean/Phrase
S8	(MH "Intensive Care, Neonatal+")	Search modes - Boolean/Phrase
S7	S1 OR S2 OR S3 OR S4 OR S6	Search modes - Boolean/Phrase
S6	S1 AND S5	Search modes - Boolean/Phrase
S5	(MH "Respiratory Distress Syndrome+")	Search modes - Boolean/Phrase
S4	TX (low birth weight or very low birth weight)	Search modes - Boolean/Phrase
S3	(MH "Infant, Low Birth Weight+")	Search modes - Boolean/Phrase
S2	TX (infan* or neonat* or neo-nat* or newborn* or baby or babies or preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie or premies)	Search modes - Boolean/Phrase
S1	(MH "Infant, Newborn+")	Search modes - Boolean/Phrase

Date of initial search: 12/02/2018

Databases(s): The Cochrane Library, issue 2 of 12, February 2018

ID	Search
#1	MeSH descriptor: [Infant, Newborn] explode all trees
#2	(infan* or neonat* or neo-nat* or newborn* or baby or babies)
#3	(preterm or pre-term or prematur* or pre-matur* or preemie* or premie* or premie*)
#4	(low near birth near/3 weigh*)
#5	MeSH descriptor: [Intensive Care, Neonatal] this term only
#6	MeSH descriptor: [Intensive Care Units, Neonatal] this term only
#7	(special and care and baby and unit*)
#9	(SCBU or NICU)
#10	{or #1-#9}
#11	MeSH descriptor: [Patient Discharge] this term only
#12	((discharg* or "post discharg*" or post-discharg*) near/3 (team* or professional* or personnel or specialist* or nurs* or MDT or key worker* or communit*))
#13	((discharg* or "post discharg*" or post-discharg*) near/3 (plan* or pathway* or pack* or program* or support* or assist* or facilitat* or "well being" or well-being or coordinat* or co-ordinat* or train* or educat* or visit* or qualification* or competen* or confiden*))
#14	((discharg* or "post discharg*" or post-discharg*) near/3 (parents or parent or family or families or mother* or maternal or father* or paternal or carer* or caregiver*))

ID	Search
#15	((discharg* or "post discharg*" or post-discharg*) near/3 (ventilat* or respirat* or breath* or oxygen* or incubat* or “nasal cannula*” or nebuli* or tracheostomy*))
#16	((discharg* or "post discharg*" or post-discharg*) near/3 (environment* or destination* or home or house or housing or electricity or medication* or fund* or equipment or device* or humidifier* or “apnea monitor*” or “apnoea monitor*"))
#17	(("follow up" or follow-up) near/2 (plan* or pack* or pathway* or program* or support* or coordinat* or co-ordinat* or visit*))
#18	transition near/3 home
#19	"discharg* summar*"
#20	{or #11-#19}
#21	#10 and #20 Publication Year from 2000 to 2018

Health economics

Date of initial search: 12/02/18

Database(s): Embase 1980 to 2018 Week 07, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh$).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez
10	neonatal respiratory distress syndrome/ use emez
11	exp Intensive Care, Neonatal/ use ppez
12	newborn intensive care/ use emez
13	exp Intensive Care Units, Neonatal/ use ppez
14	neonatal intensive care unit/ use emez
15	Neonatal Nursing/ use ppez
16	exp newborn nursing/ use emez
17	newborn care/ use emez
18	(special and care and baby and unit*).tw.
19	(SCBU or NICU).tw.
20	or/1-19
21	*hospital discharge/ use emez
22	*Patient Discharge/ use ppez
23	((discharg* or post?discharg*) adj3 (team* or professional* or personnel or specialist* or nurs* or MDT or key worker* or communit*)).tw.
24	((discharg* or post?discharg*) adj3 (plan* or pathway* or pack* or program* or support* or assist* or facilitat* or well?being or co?ordinat* or train* or educat* or visit* or qualification* or competen* or confiden*)).tw.
25	((discharg* or post?discharg*) adj2 (parents or parent or family or families or mother* or maternal or father* or paternal or carer* or caregiver*)).tw.
26	((discharg* or post?discharg*) adj3 (ventilat* or respirat* or breath* or oxygen* or incubat* or "nasal cannula*" or nebuli* or tracheostom*)).tw.
27	((discharg* or post?discharg*) adj3 (environment* or destination* or home or house or housing or electricity or medication* or fund* or equipment or device* or humidifier* or "apn?ea monitor*")).tw.
28	(follow?up adj3 (plan* or pack* or pathway* or program* or support* or co?ordinat* or visit*)).tw.
29	(transition adj3 home).tw.
30	discharge summar*.tw.
31	or/21-30
32	20 and 31
33	limit 32 to english language
34	limit 33 to yr="2000 -Current"
35	Letter/ use ppez
36	letter.pt. or letter/ use emez
37	note.pt.
38	editorial.pt.
39	Editorial/ use ppez
40	News/ use ppez
41	exp Historical Article/ use ppez
42	Anecdotes as Topic/ use ppez

#	Searches
43	Comment/ use ppez
44	Case Report/ use ppez
45	case report/ or case study/ use emez
46	(letter or comment*).ti.
47	or/35-46
48	randomized controlled trial/ use ppez
49	randomized controlled trial/ use emez
50	random*.ti,ab.
51	or/48-50
52	47 not 51
53	animals/ not humans/ use ppez
54	animal/ not human/ use emez
55	nonhuman/ use emez
56	exp Animals, Laboratory/ use ppez
57	exp Animal Experimentation/ use ppez
58	exp Animal Experiment/ use emez
59	exp Experimental Animal/ use emez
60	exp Models, Animal/ use ppez
61	animal model/ use emez
62	exp Rodentia/ use ppez
63	exp Rodent/ use emez
64	(rat or rats or mouse or mice).ti.
65	or/52-64
66	34 not 65
67	remove duplicates from 66
68	Economics/
69	Value of life/
70	exp "Costs and Cost Analysis"/
71	exp Economics, Hospital/
72	exp Economics, Medical/
73	Economics, Nursing/
74	Economics, Pharmaceutical/
75	exp "Fees and Charges"/
76	exp Budgets/
77	or/68-76 use ppez
78	health economics/
79	exp economic evaluation/
80	exp health care cost/
81	exp fee/
82	budget/
83	funding/
84	or/78-83 use emez
85	budget*.ti,ab.
86	cost*.ti.
87	(economic* or pharmaco?economic*).ti.
88	(price* or pricing*).ti,ab.
89	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
90	(financ* or fee or fees).ti,ab.
91	(value adj2 (money or monetary)).ti,ab.
92	or/85-90
93	77 or 84 or 92
94	67 and 93

Date of search: 07/0318

Database(s): Embase 1980 to 2018 Week 10, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh$).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez

#	Searches
10	neonatal respiratory distress syndrome/ use emez
11	exp Intensive Care, Neonatal/ use ppez
12	newborn intensive care/ use emez
13	exp Intensive Care Units, Neonatal/ use ppez
14	neonatal intensive care unit/ use emez
15	Neonatal Nursing/ use ppez
16	exp newborn nursing/ use emez
17	(special and care and baby and unit*).tw.
18	(SCBU or NICU).tw.
19	or/1-18
20	exp relative/ use emez
21	caregiver/ use emez
22	exp Family/ use ppez
23	Caregivers/ use ppez
24	or/20-23
25	*hospital discharge/ use emez
26	transitional care/ use emez
27	clinical handover/ use emez
28	patient care planning/ use emez
29	*Continuity of Patient Care/ use ppez
30	Patient Discharge/ use ppez or Patient Handoff/ use ppez or Patient Transfer/ use ppez or Transitional Care/ use ppez
31	*Patient Care Planning/ use ppez
32	or/25-31
33	24 and 32
34	((discharg* or transition* or transfer* or handoff or handover or "hand over") adj5 (parents or parent or parental or family or families or mother* or maternal or father* or paternal or sibling* or brother* or sister* or grandparent* or grandmother* or grandfather* or carer* or caregiver*)).tw.
35	((paediatric or pediatric) adj passport*).tw.
36	or/33-35
37	19 and 36
38	Letter/ use ppez
39	letter.pt. or letter/ use emez
40	note.pt.
41	editorial.pt.
42	Editorial/ use ppez
43	News/ use ppez
44	exp Historical Article/ use ppez
45	Anecdotes as Topic/ use ppez
46	Comment/ use ppez
47	Case Report/ use ppez
48	case report/ or case study/ use emez
49	(letter or comment*).ti.
50	or/38-49
51	randomized controlled trial/ use ppez
52	randomized controlled trial/ use emez
53	random*.ti,ab.
54	or/51-53
55	50 not 54
56	animals/ not humans/ use ppez
57	animal/ not human/ use emez
58	nonhuman/ use emez
59	exp Animals, Laboratory/ use ppez
60	exp Animal Experimentation/ use ppez
61	exp Animal Experiment/ use emez
62	exp Experimental Animal/ use emez
63	exp Models, Animal/ use ppez
64	animal model/ use emez
65	exp Rodentia/ use ppez
66	exp Rodent/ use emez
67	(rat or rats or mouse or mice).ti.
68	or/55-67
69	37 not 68
70	limit 69 to english language
71	limit 70 to yr="2000 -Current"
72	remove duplicates from 71

Date of search: 07/03/2018

Database(s): AMED (Allied and Complementary Medicine) 1985 to March 2018, Maternity & Infant Care Database (MIDIRS) 1971 to December 2017, PsycINFO 1806 to February Week 4 2018

#	Searches
1	exp infant newborn/ use amed
2	Premature Birth/ use psyh or Neonatal Period/ use psyh or Birth Weight/ use psyh
3	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
4	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
5	(low adj3 birth adj3 weigh$).tw.
6	(LBW or VLBW).tw.
7	Neonatal Intensive Care/ use psyh
8	Intensive Care Neonatal/ use amed
9	(special and care and baby and unit*).tw.
10	(SCBU or NICU).tw.
11	or/1-10
12	exp family/ use amed
13	exp Family Members/ use psyh
14	Caregivers/ use psyh
15	or/12-14
16	patient discharge/ use amed
17	continuity of patient care/ use amed
18	patient care planning/ use amed
19	Discharge Planning/ use psyh or exp Facility Discharge/ use psyh
20	Continuum of Care/ use psyh
21	Treatment Planning/ use psyh
22	or/16-21
23	15 and 22
24	((discharg* or transition* or transfer* or handoff or handover or "hand over") adj5 (parents or parent or parental or family or families or mother* or maternal or father* or paternal or sibling* or brother* or sister* or grandparent* or grandmother* or grandfather* or carer* or caregiver*)).tw.
25	((paediatric or pediatric) adj passport*).tw.
26	or/23-25
27	11 and 26
28	limit 27 to english language
29	limit 28 to yr="2000 -Current"
30	remove duplicates from 29

Date of search: 07/03/2018

Database(s): CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature) 1937-current, EBSCO Host

#	Query	Limiters/Expanders
S25	S12 AND S24	Limiters - Publication Year: 2000-2018; English Language; Exclude MEDLINE records Search modes - Boolean/Phrase
S24	S20 OR S23	Search modes - Boolean/Phrase
S23	S21 OR S22	Search modes - Boolean/Phrase
S22	TX (paediatric passport* or pediatric passport*)	Search modes - Boolean/Phrase
S21	TX ((discharg* or transition* or transfer* or handoff or handover or "hand over") N5 (parents or parent or parental or family or families or mother* or maternal or father* or paternal or sibling* or brother* or sister* or grandparent* or grandmother* or grandfather* or carer* or caregiver*))	Search modes - Boolean/Phrase
S20	S15 AND S19	Search modes - Boolean/Phrase
S19	S16 OR S17 OR S18	Search modes - Boolean/Phrase
S18	(MH "Continuity of Patient Care+")	Search modes - Boolean/Phrase
S17	(MH "Transitional Care")	Search modes - Boolean/Phrase
S16	(MH "Patient Discharge+")	Search modes - Boolean/Phrase
S15	S13 OR S14	Search modes - Boolean/Phrase
S14	(MH "Caregivers")	Search modes - Boolean/Phrase
S13	(MH "Family+")	Search modes - Boolean/Phrase
S12	S7 OR S8 OR S9 OR S10 OR S11	Search modes - Boolean/Phrase
S11	TX (SCBU or NICU)	Search modes - Boolean/Phrase
S10	TX (special and care and baby and unit*)	Search modes - Boolean/Phrase
S9	(MH "Intensive Care Units, Neonatal")	Search modes - Boolean/Phrase
S8	(MH "Intensive Care, Neonatal+")	Search modes - Boolean/Phrase
S7	S1 OR S2 OR S3 OR S4 OR S6	Search modes - Boolean/Phrase
S6	S1 AND S5	Search modes - Boolean/Phrase

#	Query	Limiters/Expanders
S5	(MH "Respiratory Distress Syndrome+")	Search modes - Boolean/Phrase
S4	TX (low birth weight or very low birth weight)	Search modes - Boolean/Phrase
S3	(MH "Infant, Low Birth Weight+")	Search modes - Boolean/Phrase
S2	TX (infan* or neonat* or neo-nat* or newborn* or baby or babies or preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie or premies)	Search modes - Boolean/Phrase
S1	(MH "Infant, Newborn+")	Search modes - Boolean/Phrase

Date of search: 07/03/2018

Databases(s): The Cochrane Library, issue 3 of 12, March 2018

ID	Search
#1	MeSH descriptor: [Infant, Newborn] explode all trees
#2	(infan* or neonat* or neo-nat* or newborn* or baby or babies)
#3	(preterm or pre-term or prematur* or pre-matur* or preemie* or premie* or premie*)
#4	(low next birth near/3 weigh*)
#5	MeSH descriptor: [Intensive Care, Neonatal] this term only
#6	MeSH descriptor: [Intensive Care Units, Neonatal] this term only
#7	(special and care and baby and unit*)
#8	((newborn or neonatal or neo-natal) near/2 (ICU or ICUs or unit*))
#9	(SCBU or NICU)
#10	{or #1-#9}
#11	MeSH descriptor: [Family] explode all trees
#12	MeSH descriptor: [Caregivers] this term only
#13	{or #11-#12}
#14	MeSH descriptor: [Continuity of Patient Care] explode all trees
#15	MeSH descriptor: [Patient Care Planning] this term only
#16	{or #14-#15}
#17	#13 and #16
#18	((discharg* or transition* or transfer* or handoff or handover or "hand over") near/5 (parents or parent or parental or family or families or mother* or maternal or father* or paternal or sibling* or brother* or sister* or grandparent* or grandmother* or grandfather* or carer* or caregiver*))
#19	("paediatric passport*" or "pediatric passport*")
#20	{or #17-#19}
#21	#10 and #20 Publication Year from 2000 to 2018

Health economics

Date of search: 08/03/18

Database(s): Embase 1980 to 2018 Week 10, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh$).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez
10	neonatal respiratory distress syndrome/ use emez
11	exp Intensive Care, Neonatal/ use ppez
12	newborn intensive care/ use emez
13	exp Intensive Care Units, Neonatal/ use ppez
14	neonatal intensive care unit/ use emez
15	Neonatal Nursing/ use ppez
16	exp newborn nursing/ use emez
17	(special and care and baby and unit*).tw.
18	(SCBU or NICU).tw.
19	or/1-18
20	exp relative/ use emez
21	caregiver/ use emez
22	exp Family/ use ppez
23	Caregivers/ use ppez
24	or/20-23

#	Searches
25	*hospital discharge/ use emez
26	transitional care/ use emez
27	clinical handover/ use emez
28	patient care planning/ use emez
29	*Continuity of Patient Care/ use ppez
30	Patient Discharge/ use ppez or Patient Handoff/ use ppez or Patient Transfer/ use ppez or Transitional Care/ use ppez
31	*Patient Care Planning/ use ppez
32	or/25-31
33	24 and 32
34	((discharg* or transition* or transfer* or handoff or handover or "hand over") adj5 (parents or parent or parental or family or families or mother* or maternal or father* or paternal or sibling* or brother* or sister* or grandparent* or grandmother* or grandfather* or carer* or caregiver*)).tw.
35	((paediatric or pediatric) adj passport*).tw.
36	or/33-35
37	19 and 36
38	Economics/
39	Value of life/
40	exp "Costs and Cost Analysis"/
41	exp Economics, Hospital/
42	exp Economics, Medical/
43	Economics, Nursing/
44	Economics, Pharmaceutical/
45	exp "Fees and Charges"/
46	exp Budgets/
47	(or/38-46) use ppez
48	health economics/
49	exp economic evaluation/
50	exp health care cost/
51	exp fee/
52	budget/
53	funding/
54	(or/48-53) use emez
55	budget*.ti,ab.
56	cost*.ti.
57	(economic* or pharmaco?economic*).ti.
58	(price* or pricing*).ti,ab.
59	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
60	(financ* or fee or fees).ti,ab.
61	(value adj2 (money or monetary)).ti,ab.
62	or/55-60
63	47 or 54 or 62
64	37 and 63
65	limit 64 to english language
66	limit 65 to yr="2000 -Current"
67	remove duplicates from 66

Literature search strategies for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

Date of search: 07/03/2018

Database(s): Embase 1980 to 2018 Week 10, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh$).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez
10	neonatal respiratory distress syndrome/ use emez

#	Searches
11	exp Intensive Care, Neonatal/ use ppez
12	newborn intensive care/ use emez
13	exp Intensive Care Units, Neonatal/ use ppez
14	neonatal intensive care unit/ use emez
15	Neonatal Nursing/ use ppez
16	exp newborn nursing/ use emez
17	(special and care and baby and unit*).tw.
18	(SCBU or NICU).tw.
19	or/1-18
20	exp relative/ use emez
21	caregiver/ use emez
22	exp Family/ use ppez
23	Caregivers/ use ppez
24	or/20-23
25	*hospital discharge/ use emez
26	transitional care/ use emez
27	clinical handover/ use emez
28	patient care planning/ use emez
29	*Continuity of Patient Care/ use ppez
30	Patient Discharge/ use ppez or Patient Handoff/ use ppez or Patient Transfer/ use ppez or Transitional Care/ use ppez
31	*Patient Care Planning/ use ppez
32	or/25-31
33	24 and 32
34	((discharg* or transition* or transfer* or handoff or handover or "hand over") adj5 (parents or parent or parental or family or families or mother* or maternal or father* or paternal or sibling* or brother* or sister* or grandparent* or grandmother* or grandfather* or carer* or caregiver*)).tw.
35	((paediatric or pediatric) adj passport*).tw.
36	or/33-35
37	19 and 36
38	Letter/ use ppez
39	letter.pt. or letter/ use emez
40	note.pt.
41	editorial.pt.
42	Editorial/ use ppez
43	News/ use ppez
44	exp Historical Article/ use ppez
45	Anecdotes as Topic/ use ppez
46	Comment/ use ppez
47	Case Report/ use ppez
48	case report/ or case study/ use emez
49	(letter or comment*).ti.
50	or/38-49
51	randomized controlled trial/ use ppez
52	randomized controlled trial/ use emez
53	random*.ti,ab.
54	or/51-53
55	50 not 54
56	animals/ not humans/ use ppez
57	animal/ not human/ use emez
58	nonhuman/ use emez
59	exp Animals, Laboratory/ use ppez
60	exp Animal Experimentation/ use ppez
61	exp Animal Experiment/ use emez
62	exp Experimental Animal/ use emez
63	exp Models, Animal/ use ppez
64	animal model/ use emez
65	exp Rodentia/ use ppez
66	exp Rodent/ use emez
67	(rat or rats or mouse or mice).ti.
68	or/55-67
69	37 not 68
70	limit 69 to english language
71	limit 70 to yr="2000 -Current"
72	remove duplicates from 71

Date of search: 07/03/2018

Database(s): AMED (Allied and Complementary Medicine) 1985 to March 2018, Maternity & Infant Care Database (MIDIRS) 1971 to December 2017, PsycINFO 1806 to February Week 4 2018

#	Searches
1	exp infant newborn/ use amed
2	Premature Birth/ use psyh or Neonatal Period/ use psyh or Birth Weight/ use psyh
3	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
4	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
5	(low adj3 birth adj3 weigh$).tw.
6	(LBW or VLBW).tw.
7	Neonatal Intensive Care/ use psyh
8	Intensive Care Neonatal/ use amed
9	(special and care and baby and unit*).tw.
10	(SCBU or NICU).tw.
11	or/1-10
12	exp family/ use amed
13	exp Family Members/ use psyh
14	Caregivers/ use psyh
15	or/12-14
16	patient discharge/ use amed
17	continuity of patient care/ use amed
18	patient care planning/ use amed
19	Discharge Planning/ use psyh or exp Facility Discharge/ use psyh
20	Continuum of Care/ use psyh
21	Treatment Planning/ use psyh
22	or/16-21
23	15 and 22
24	((discharg* or transition* or transfer* or handoff or handover or "hand over") adj5 (parents or parent or parental or family or families or mother* or maternal or father* or paternal or sibling* or brother* or sister* or grandparent* or grandmother* or grandfather* or carer* or caregiver*)).tw.
25	((paediatric or pediatric) adj passport*).tw.
26	or/23-25
27	11 and 26
28	limit 27 to english language
29	limit 28 to yr="2000 -Current"
30	remove duplicates from 29

Date of search: 07/03/2018

Database(s): CINAHL Plus (Cumulative Index to Nursing and Allied Health Literature) 1937-current, EBSCO Host

#	Query	Limiters/Expanders
S25	S12 AND S24	Limiters - Publication Year: 2000-2018; English Language; Exclude MEDLINE records Search modes - Boolean/Phrase
S24	S20 OR S23	Search modes - Boolean/Phrase
S23	S21 OR S22	Search modes - Boolean/Phrase
S22	TX (paediatric passport* or pediatric passport*)	Search modes - Boolean/Phrase
S21	TX ((discharg* or transition* or transfer* or handoff or handover or "hand over") N5 (parents or parent or parental or family or families or mother* or maternal or father* or paternal or sibling* or brother* or sister* or grandparent* or grandmother* or grandfather* or carer* or caregiver*))	Search modes - Boolean/Phrase
S20	S15 AND S19	Search modes - Boolean/Phrase
S19	S16 OR S17 OR S18	Search modes - Boolean/Phrase
S18	(MH "Continuity of Patient Care+")	Search modes - Boolean/Phrase
S17	(MH "Transitional Care")	Search modes - Boolean/Phrase
S16	(MH "Patient Discharge+")	Search modes - Boolean/Phrase
S15	S13 OR S14	Search modes - Boolean/Phrase
S14	(MH "Caregivers")	Search modes - Boolean/Phrase
S13	(MH "Family+")	Search modes - Boolean/Phrase
S12	S7 OR S8 OR S9 OR S10 OR S11	Search modes - Boolean/Phrase
S11	TX (SCBU or NICU)	Search modes - Boolean/Phrase
S10	TX (special and care and baby and unit*)	Search modes - Boolean/Phrase
S9	(MH "Intensive Care Units, Neonatal")	Search modes - Boolean/Phrase
S8	(MH "Intensive Care, Neonatal+")	Search modes - Boolean/Phrase
S7	S1 OR S2 OR S3 OR S4 OR S6	Search modes - Boolean/Phrase
S6	S1 AND S5	Search modes - Boolean/Phrase

#	Query	Limiters/Expanders
S5	(MH "Respiratory Distress Syndrome+")	Search modes - Boolean/Phrase
S4	TX (low birth weight or very low birth weight)	Search modes - Boolean/Phrase
S3	(MH "Infant, Low Birth Weight+")	Search modes - Boolean/Phrase
S2	TX (infan* or neonat* or neo-nat* or newborn* or baby or babies or preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie or premies)	Search modes - Boolean/Phrase
S1	(MH "Infant, Newborn+")	Search modes - Boolean/Phrase

Date of search: 07/03/2018

Databases(s): The Cochrane Library, issue 3 of 12, March 2018

ID	Search
#1	MeSH descriptor: [Infant, Newborn] explode all trees
#2	(infan* or neonat* or neo-nat* or newborn* or baby or babies)
#3	(preterm or pre-term or prematur* or pre-matur* or preemie* or premie* or premie*)
#4	(low next birth near/3 weigh*)
#5	MeSH descriptor: [Intensive Care, Neonatal] this term only
#6	MeSH descriptor: [Intensive Care Units, Neonatal] this term only
#7	(special and care and baby and unit*)
#8	((newborn or neonatal or neo-natal) near/2 (ICU or ICUs or unit*))
#9	(SCBU or NICU)
#10	{or #1-#9}
#11	MeSH descriptor: [Family] explode all trees
#12	MeSH descriptor: [Caregivers] this term only
#13	{or #11-#12}
#14	MeSH descriptor: [Continuity of Patient Care] explode all trees
#15	MeSH descriptor: [Patient Care Planning] this term only
#16	{or #14-#15}
#17	#13 and #16
#18	((discharg* or transition* or transfer* or handoff or handover or "hand over") near/5 (parents or parent or parental or family or families or mother* or maternal or father* or paternal or sibling* or brother* or sister* or grandparent* or grandmother* or grandfather* or carer* or caregiver*))
#19	("paediatric passport*" or "pediatric passport*")
#20	{or #17-#19}
#21	#10 and #20 Publication Year from 2000 to 2018

Health economics

Date of search: 08/03/2018

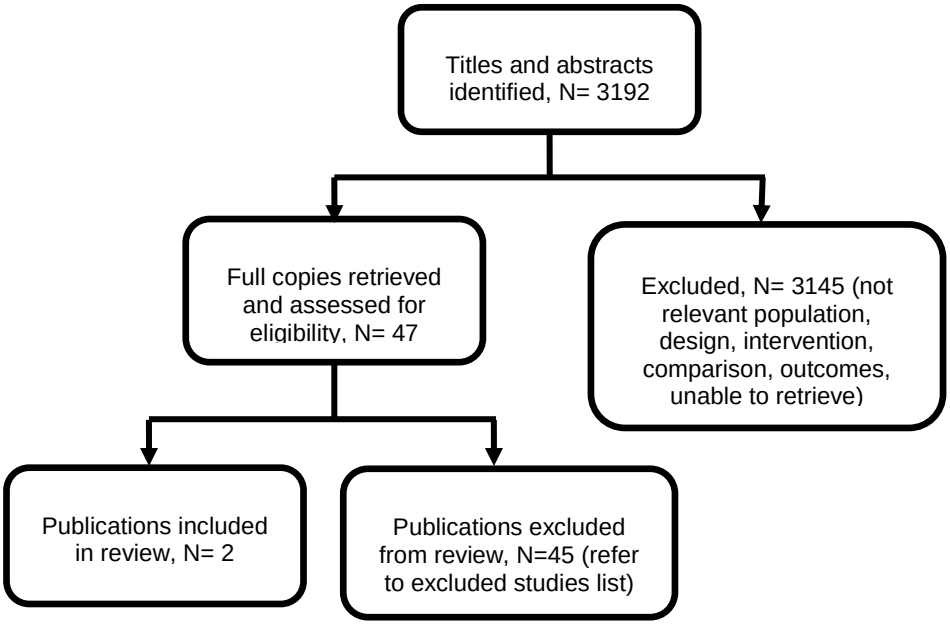
Database(s): Embase 1980 to 2018 Week 10, Ovid MEDLINE(R) Epub Ahead of Print, In-Process & Other Non-Indexed Citations, Ovid MEDLINE(R) Daily and Ovid MEDLINE(R) 1946 to Present

#	Searches
1	exp Infant, Newborn/ use ppez
2	newborn/ use emez
3	prematurity/ use emez
4	(infan* or neonat* or neo-nat* or newborn* or baby or babies).ti,ab,jw,nw.
5	(preterm or pre-term or prematur* or pre-matur* or pre?mie* or premie*1).tw.
6	exp low birth weight/ use emez
7	(low adj3 birth adj3 weigh$).tw.
8	(LBW or VLBW).tw.
9	exp Respiratory Distress Syndrome, Newborn/ use ppez
10	neonatal respiratory distress syndrome/ use emez
11	exp Intensive Care, Neonatal/ use ppez
12	newborn intensive care/ use emez
13	exp Intensive Care Units, Neonatal/ use ppez
14	neonatal intensive care unit/ use emez
15	Neonatal Nursing/ use ppez
16	exp newborn nursing/ use emez
17	(special and care and baby and unit*).tw.
18	(SCBU or NICU).tw.
19	or/1-18
20	exp relative/ use emez
21	caregiver/ use emez
22	exp Family/ use ppez
23	Caregivers/ use ppez
24	or/20-23

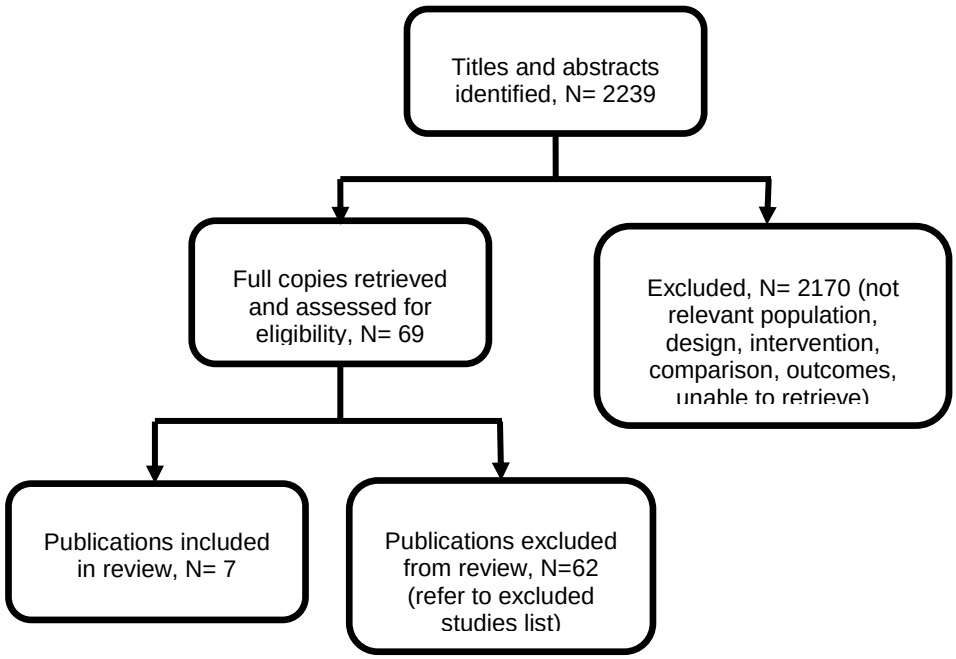
#	Searches
25	*hospital discharge/ use emez
26	transitional care/ use emez
27	clinical handover/ use emez
28	patient care planning/ use emez
29	*Continuity of Patient Care/ use ppez
30	Patient Discharge/ use ppez or Patient Handoff/ use ppez or Patient Transfer/ use ppez or Transitional Care/ use ppez
31	*Patient Care Planning/ use ppez
32	or/25-31
33	24 and 32
34	((discharg* or transition* or transfer* or handoff or handover or "hand over") adj5 (parents or parent or parental or family or families or mother* or maternal or father* or paternal or sibling* or brother* or sister* or grandparent* or grandmother* or grandfather* or carer* or caregiver*)).tw.
35	((paediatric or pediatric) adj passport*).tw.
36	or/33-35
37	19 and 36
38	Economics/
39	Value of life/
40	exp "Costs and Cost Analysis"/
41	exp Economics, Hospital/
42	exp Economics, Medical/
43	Economics, Nursing/
44	Economics, Pharmaceutical/
45	exp "Fees and Charges"/
46	exp Budgets/
47	(or/38-46) use ppez
48	health economics/
49	exp economic evaluation/
50	exp health care cost/
51	exp fee/
52	budget/
53	funding/
54	(or/48-53) use emez
55	budget*.ti,ab.
56	cost*.ti.
57	(economic* or pharmaco?economic*).ti.
58	(price* or pricing*).ti,ab.
59	(cost* adj2 (effective* or utilit* or benefit* or minimi* or unit* or estimat* or variable*)).ab.
60	(financ* or fee or fees).ti,ab.
61	(value adj2 (money or monetary)).ti,ab.
62	or/55-60
63	47 or 54 or 62
64	37 and 63
65	limit 64 to english language
66	limit 65 to yr="2000 -Current"
67	remove duplicates from 66

Appendix C – Clinical evidence study selection

Clinical evidence study selection for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?



Clinical evidence study selection for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?



Appendix D – Clinical evidence tables

Clinical evidence tables for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

Study details	Participants	Methods	Themes	Quality assessment
Full citation Helder, O. K., Verweij, J. C., van Staa, A., Transition from neonatal intensive care unit to special care nurseries: experiences of parents and nurses, Pediatric Critical Care Medicine, 13, 305-11, 2012 **Ref Id** 694892 **Country/ies where the study was carried out** the Netherlands **Study type** Semi-structured interviews **Aim of the study** The aim of the study was to assess parents' and nurses' experiences with	**Sample size** N=18 **Characteristics** Not applicable **Inclusion criteria** Not reported **Exclusion criteria** Not reported **Interventions** Not applicable	**Details** Three nurses from the NICU and 3 from each Specialist Care Nursery (SCN) were interviewed. Nurses provided written informed consent at the time of the interview. **Sampling** Sampling method not reported **Setting** 5 level 2 SCNs in the Netherlands **Data collection** The interview guide was developed from a literature review and refined during the interviews. Interviews were conducted by pairs of nursing students under supervision from the second author. Interviews were audio-recorded and transcribed verbatim.	**Results** Preparing parents for baby's daily care needs -Mentally Practical aspects -Transportation -Home set up	**Limitations** Potential selection bias from use of convenience sampling **Other information** The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Can't tell (researchers did not describe recruitment strategy of nurse participants) 5. Was the data collected in

Study details	Participants	Methods	Themes	Quality assessment
the transition of babies from the NICU to a special care nursery **Study dates** 2005-2008 **Source of funding** Not reported		**Data analysis** Thematic analysis was performed with researchers first analysing the parents' interviews. Researchers read the interviews to familiarise themselves with the data and then fored codes across the data. Codes were modified, expanded or merged and were collated to identify potential themes. Next, Nurses' transcript were assessing using relevant subthemes of the final coding framework developed from the parents' interviews. Peer debriefing amongst researchers and respondent validation were used to ensure validity of the analysis. An external auditor provided feedback on the themes.		a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research) 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary
Full citation Hobbs, J. E., Tschudy, M. M., Hussey-Gardner, B., Jennings, J. M., Boss, R. D., "I don't know what I was expecting": Home visits by neonatology fellows for infants discharged from the NICU, Birth, 22, 22, 2017	**Sample size** N= 10 **Characteristics** Neonatology fellows, n= 10 Female, n= 10 Postgraduate year 4-7 Early to mid 30s	**Details** The study coordinator organised home visits 4-6 weeks post-NICU discharge. **Sampling** Not reported	**Results** Preparing parents for the baby's daily care needs -Mentally -Practically Practical aspects -Transportation -Home set up	**Limitations** Fellows chose which families participated in the home visit program so participants did not reflect the diversity of the NICU population. **Other information**

Study details	Participants	Methods	Themes	Quality assessment
Ref Id 694916 **Country/ies where the study was carried out** US **Study type** Semi-structured interviews **Aim of the study** The aim of the study was to assess the influence of a home visiting program on neonatology fellows' understanding of family needs soon after hospital discharge. **Study dates** June 2013 to January 2015 **Source of funding** Not reported	Babies, n=10 Gestational age, weeks, median (IQR)= 36.5 (23-40) Male, n (%)= 5 (50) Diagnosis, n (%) Congenital anomaly= 3 (30) Prematurity= 2 (20) Hypoxic ischemic encephalopathy= 1 (10) Evaluation for sepsis= 2 (20) Hypoglycemia= 1 (10) Pulmonary embolus= 1 (10) Discharged with durable medical equipment, n (%)= 4 (40) **Inclusion criteria** Fellows: preparing a baby for discharge from the NICU Babies: Eligible babies had been in the NICU for at least 1 week, had English-speaking parents, lived in the Baltimore metropolitan area. **Exclusion criteria** Not reported **Interventions** The Health Begins at Home intervention was adapted for use in the neonatology fellowship training. At the start of the home visit program, fellows	**Setting** Parents' homes **Data collection** During travel to and from homes, fellows observed the neighbourhood and community resources surrounding the family's neighbourhood and community resources, such as where parents would go to buy food and supplies for the baby. After the home visit, fellows completed semi-structured interviews that were audio-recorded and transcribed. **Data analysis** Transcripts were assessed by 2 researchers and manually coded and similar codes were grouped. Discrepancies in codes were resolved by consensus. Illustrative quotes were included in the write up, but were edited for clarity and to preserve anonymity.	Interpersonal aspects -Normalising -Clear and simple communication with parents -Understanding the context	The assessment of the quality of the study was performed using the CASP checklist for qualitative studies 1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Can't tell (recruitment strategy not reported) 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research) 7. Have ethical issues been taken into consideration? Can't tell (insufficient evidence to determine whether ethical standards were maintained; parents

Study details	Participants	Methods	Themes	Quality assessment
	participated in a two hour training session that reviewed potential benefits of home visits, outlined goals, etc. Before the home visit the fellow reviewed the NICU discharge plans that they had made for the specific infant, focusing on those elements that required special care by the family. Fellows were accompanied by the study coordinator. Fellows began by reviewing with the parents the infant's NICU discharge plans, the fellows discussed with parents about their challenges and also observed the family's organisation of the infant's medical equipment, daily care supplies, and sleeping space.			received a developmental play mat, toys and a book for their baby for their participation) 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Clinical evidence tables for question 7.2 What are the support and information needs of parents and carers of preterm babies transitioning from the neonatal unit while receiving respiratory support?

Study details	Participants	Methods	Themes	Comments

Full citation
 	
Burnham,N., Feeley,N., Sherrard,K., Parents' perceptions regarding readiness for their infant's discharge from the NICU, Neonatal Network, 32, 324-334, 2013
	Sample size
	N=20
	
	Characteristics
	Parents, n= 20
	Female, n (%)= 16 (80)
	Age, years, mean (SD)= 35.9 (5.7)
		Details
		After the study received ethical approval, potential participants were during the baby's hospitalisation by the Clinical Nurse Specialist to explain the study and obtain permission for the first author to make contact. If both parents of a baby participated, they were
			Results
			Information needs
			
			• Preparation
			  ○ How to prepare the home
			  ○ Hands on experience in the NICU
				Limitations
				Limited generalisability due to participants coming from one urban setting, participants being older and well-educated and living with their partners. All babies were stable at the time of interviews; not known whether parents of

Study details	Participants	Methods	Themes	Comments

Ref Id
 	
325123
 	
Country/ies where the study was carried out
 	
Canada
 	
Study type
Semi-structured interviews
 	
Aim of the study
The aim of the study was to explore what parents need in order to feel ready for the discharge of their baby from the NICU
 	
Study dates
2011-2012
 	
Source of funding
Quebec Minister of Education, Recreation and Sports; Quebec Interuniversity Nursing Intervention Group; Fund for Quebec Research-Health
	Education
	Junior college or less, n (%)= 5 (25)
	Trade/technical program certificate, n (%)= 1 (5)
	University, n (%)= 14 (70)
	Babies, n=24
	Gestational age, weeks, mean (SD)=31.1 (3.1)
	Birth weight, grams, mean (SD)=1436.9 (488.1)
	Mechanical ventilation, n (%)= 6 (33.3)
	CPAP/HFNC, n (%)= 15 (62.5)
	Intravenous or central line, n (%)= 22 (91.7)
	Chest tube, n (%)= 1 (6.3)
	Gavage/total parenteral nutrition, n (%)= 2 (87.5)
	
	Inclusion criteria
	18 years of age or older, speak English or French, with babies who were stable, as determined by a clinician and in the parents' care after discharge.
	
	Exclusion criteria
	Parents of infants who were diagnosed with grade IV intraventricular haemorrhage, diagnosed with trisomy 21 malformation, being transferred
		interviewed separately and each counted as a participant.
		
		Sampling
		Recruitment was conducted using maximum variation sampling at two different time points - predischarge and postdischarge.
		
		Setting
		At the hospital in a private room or at the parents' homes
		
		Data collection
		Participants completed a demographic questionnaire. Semi-structured interviews were performed in person and lasted one hour. Participants in the predischarge group were interviewed prior to going home with the baby and parents in the postdischarge group were interviewed 3-8 weeks after being discharged. Interviews were audio-recorded and transcribed verbatim.
		
		Data analysis
			• Routine care
			  ○ Physiological needs
			  ○ How to tell if baby is doing well
			  ○ What to do if something goes wrong
			  ○ Medical information specific to baby's condition
			• Follow up
			• Format
			  ○ Timing
			  ○ Resource
			  ○ Personnel
			
			Support needs
			
			• Medical staff support
			  ○ Being able to contact about questions
			  ○ Self care
			  ○ Feeling ready
			  ○ Trust and security
				sicker babies would have different needs.
				
				Other information
				The assessment of the quality of the study was performed using the CASP checklist for qualitative studies
				1. Was there a clear statement of the aims of the research?
				2. Is a qualitative methodology appropriate?
				3. Was the research design appropriate to address the aims of the research?
				4. Was the recruitment strategy appropriate to the aims of the research?
				5. Was the data collected in a way that addressed the research issue?
				6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research)
				7. Have ethical issues been taken into

Study details	Participants	Methods	Themes	Comments
	to the children's hospital, palliative, and born to mothers suffering from addiction **Interventions** Not applicable	First interviews were read over multiple times. NVivo software was used to perform open coding. The list of categories was examined by the researchers and categories were collapsed into broader subheadings. Subheadings were organised into higher-order themes. Credibility, dependability, confirmability and transferability were assessed to ensure the trustworthiness of the study data.		consideration? 8. Was the data analysis sufficiently rigorous? 9. Is there a clear statement of findings? 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Full citation
 	
Dellenmark-Blom, Michaela, Wigert, Helena, Parents' experiences with neonatal home care following initial care in the neonatal intensive care unit: A phenomenological hermeneutical interview study, J Adv NursJournal of advanced nursing, 70, 575-586, 2014
 	
Ref Id
 	
800591
 	
Country/ies where the study was carried out
 	
Sweden
	Sample size
	N=22
	
	Characteristics
	Parents, n= 22
	Mother, n (%)= 15 (68.2)
	First time parent, n (%)= 18 (81.8)
	Baby, n=18
	Male sex, n (%)= 9 (50)
	Gestational age, weeks, median (IQR)= 33.5 (25-37)
	Birth weight, grams, median (IQR)= 1947.5 (870-3200)
	Medical treatment in the NICU, n (%)
	Mechanical ventilation= 2 (11.1)
	Nasal CPAP= 5 (27.8)
	Intravenous drug= 11 (61.1)
	Nasogastric tube= 18 (100)
		Details
		Using medical records, nearly 200 families were identified as meeting inclusion criteria. Prior to NICU discharge, parents had to have received education and training tailored to their baby's specific needs and had to have stayed with the baby in a family room in the NICU for more than 2 nights.
		
		Sampling
		Purposive sampling was used to ensure variability amongst participants in terms of infant sex, gestational age at birth, birth weight and length of stay in the NICU and NHC. Prospective participants were contacted.
			Results
			Information needs
			
			• Routine care
			  ○ How to tell if baby is doing well
			
			Support needs
			
			• Medical staff support
			  ○ Being able to contact about questions
			  ○ Building confidence
			  ○ Trust and security
				Limitations
				Findings may not be applicable to other health care contexts where health insurance and health delivery promote the presence of parents during the baby's hospital stay. Some parents were interviewed together and this could have caused interference amongst narratives.
				
				Other information
				The assessment of the quality of the study was performed using the CASP checklist for qualitative studies

Study details	Participants	Methods	Themes	Comments
Study type Open-ended interviews **Aim of the study** The aim of the study was to explore parents' experiences with neonatal home care following care in the NICU **Study dates** 2011-2012 **Source of funding** Swedish government grants for medical resaearch; scholarships from the Swedish National Association for Pediatric Nurses, the Foundation of Herbery and Karin Jacobsson and Mary von Sydow	**Inclusion criteria** The baby's initial neonatal care took place in a level III NICU and was followed by care in the NHC, interviews took place within 12 months of discharge from the NHC, and parents spoke and understood Swedish **Exclusion criteria** Not reported **Interventions** Not applicable	**Setting** Parents' homes **Data collection** Open-ended interviews were audio-recorded and transcribed verbatim. Interviews were 26-52 minutes and were started with similar questions aimed to probe the parents to go in depth in their experiences. **Data analysis** Using a phenomenological hermeneutic method, the data was first analysed by reading the transcriptions several times. Then the texts were divided into meaning units, which were condensed into preliminary subthemes and themes. Meanings were discussed until the researchers agreed. Validity was strengthened through discussions among the researchers about the relationship between parts and the whole of the text.		1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Yes 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary.

Study details	Participants	Methods	Themes	Comments

Full citation
 	
Helder, O. K., Verweij, J. C. M., Van Staa, A., Transition from neonatal intensive care unit to special care nurseries: Experiences of parents and nurses, Pediatric Critical Care Medicine, 13, 305-311, 2012
 	
Ref Id
 	
683933
 	
Country/ies where the study was carried out
 	
the Netherlands
 	
Study type
Semi-structured interviews
 	
Aim of the study
The aim of the study was to assess parents' and nurses' experiences with the transition of babies from the NICU to a special care nursery
 	
Study dates
	Sample size
	N= 28
	
	Characteristics
	Parents, n=28
	Mothers, n (%)= 21 (75)
	Non-Dutch ethnic background, n (%)= 7 (25)
	Mother's age, years, mean (SD)= 31.2 (4.6)
	Babies, n=24
	Gestational age, weeks, median (IQR)= 30.7 (26.0-39.4)
	Birth weight, grams, median (IQR)= 1780 (635-4000)
	Female, n (%)= 16 (66.7)
	CRIB score, mean (SD)= 2 (0.5)
	
	Inclusion criteria
	Parents of babies transferred from the NICU to one of five SCNs in the region in the last six months of 2005.
	
	Exclusion criteria
	Not reported
	
	Interventions
		Details
		The first author first called eligible parents to see if they wanted to participate in the study. If they agreed, an interview time was arranged. Interviews were conducted by pairs of nursing students under supervision of the second author.
		
		Sampling
		Convenience sampling was used
		
		Setting
		5 level 2 SCNs in the Netherlands
		
		Data collection
		The interview guide was developed from a literature review and refined during the interviews. Interviews were conducted by pairs of nursing students under supervision from the second author. Interviews were audio-recorded and transcribed verbatim.
		
		Data analysis
			Results
			Information needs
			
			• Preparation
			  ○ Transportation from NICU
			
			Support needs
			
			• Medical staff support
			  ○ Trust and security
				Limitations
				Potential selection bias from use of convenience sampling
				
				Other information
				The assessment of the quality of the study was performed using the CASP checklist for qualitative studies
				1. Was there a clear statement of the aims of the research? Yes
				2. Is a qualitative methodology appropriate? Yes
				3. Was the research design appropriate to address the aims of the research? Yes
				4. Was the recruitment strategy appropriate to the aims of the research? Yes
				5. Was the data collected in a way that addressed the research issue? Yes
				6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they

Study details	Participants	Methods	Themes	Comments
2005-2008 **Source of funding** Not reported	Not applicable	Thematic analysis was performed with researchers first analysing the parents' interviews. Researchers read the interviews to familiarise themselves with the data and then formed codes across the data. Codes were modified, expanded or merged and were collated to identify potential themes. Next, Nurses' transcript were assessing using relevant subthemes of the final coding framework developed from the parents' interviews. Peer debriefing amongst researchers and respondent validation were used to ensure validity of the analysis. An external auditor provided feedback on the themes.		critically examined their own role in the research) 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Full citation
 	
Lindberg,B., Axelsson,K., Ohrling,K., Experience with videoconferencing between a neonatal unit and the families' home from the perspective of certified paediatric nurses, Journal of Telemedicine and Telecare, 15, 275-280, 2009
 	
Ref Id
 	
307020
	Sample size
	N=20
	
	Characteristics
	Parents, n= 20
	Mothers, n (%)= 10 (50)
	Mother's age, years, median (IQR)= 33.5 (28-39)
	Father's age, years, median (IQR)= 37.5 (29-44)
	First time parents, n (%)= 12 (60)
	Babies, n= 10
		Details
		Parents received information on the study from the paediatric nurse, in both written and verbal form. Parents who met inclusion criteria were shown how to use the videoconferencing equipment.
		
		Sampling
		Purposive sampling used
			Results
			Support needs
			
			• Medical staff support
			  ○ Being able to contact about questions
			  ○ Feeling ready
			  ○ Trust and security
				Limitations
				Did not report
				
				Other information
				The assessment of the quality of the study was performed using the CASP checklist for qualitative studies
				1. Was there a clear statement of the aims of the research? Yes
				2. Is a qualitative methodology appropriate?

Study details	Participants	Methods	Themes	Comments
Country/ies where the study was carried out Sweden **Study type** Semi-structured interviews **Aim of the study** The aim of the study was to assess the experiences of parents of preterm babies on the use of real-time videoconferencing between their home and the NICU. **Study dates** Not reported **Source of funding** Centre for Distance-Spanning Health Care; Norrbotten County Council	Gestational age, weeks, range= 24-33 Gestational age at discharge, range= 34-39 **Inclusion criteria** Being parents of a preterm baby born at 34 weeks gestation or less and needing care in the NICU, both parents in the couple had to agree to participants, access to internet or ADSL from home. **Exclusion criteria** Not reported **Interventions** The intervention included real-time video-conferencing which enabled communication between the parents' homes and the NICU. The intervention took place from September 2006-2007. Parents were encouraged to access the videoconferencing day and night, whenever they needed or wanted. The total amount of contacts varied between the parents, from 2 to about 30.	**Setting** In the NICU or over the phone **Data collection** Data were collected from interviews and notes. The parents were interviewed together. The parents were encouraged to talk freely about their own experiences on the use of the video conferencing. Interviews lasted 30-60 minutes, were audio recorded and were transcribed verbatim. **Data analysis** Thematic content analysis was used to assess the data. Each interview was read several times and then meaning units were attached to the text. Units were condensed and grouped into categories. Categories were linked.		Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Can't tell (did not explain why the participants they selected were the most appropriate to provide access to the type of knowledge sought by the study) 5. Was the data collected in a way that addressed the research issue? 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research) 7. Have ethical issues been taken into consideration? 8. Was the data analysis sufficiently rigorous? Can't tell (Authors did not discuss triangulation to ensure credibility) 9. Is there a clear statement of findings?

Study details	Participants	Methods	Themes	Comments
				Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Full citation
 	
Murdoch, Marlies R., Franck, Linda S., Gaining confidence and perspective: A phenomenological study of mothers' lived experiences caring for infants at home after neonatal unit discharge, Journal of Advanced Nursing, 68, 2008-2020, 2012
 	
Ref Id
 	
695494
 	
Country/ies where the study was carried out
 	
Canada
 	
Study type
Semi-structured interviews
	Sample size
	N= 9
	
	Characteristics
	Mothers, n= 9
	Age, years, median (IQR)= 34 (27-42)
	First pregnancy, n (%)= 6 (66%)
	Ethnicity, n (%)
	White British= 6
	Black= 1
	Middle Eastern= 1
	White= 1
	Infants, n=10 (one set of twins)
	Male, n (%)= 6 (60)
	Gestational age, weeks, median (IQR)= 31 (24-42)
	Diagnoses, n (%)
	Preterm= 8 (80)
	Chronic lung disease= 4 (40)
	Patent ductus arteriosus= 4 (40)
	Respiratory distress syndrome= 2 (20)
	Trisomy 21= 1 (10)
		Details
		Twenty mothers responded to the invitation letter; 9 were eligible to participate.
		
		Sampling
		Opportunistic sampling was used; a letter was mailed to 40 consecutive members who had returned the postdischarge survey for the RCT, regardless of group assignment.
		
		Setting
		Participant's home or over the phone
		
		Data collection
		Interviews were audio-recorded. Interviewers used an interview guide that was developed from previous studies. Data was
			Results
			Information needs
			
			• Routine care
			  ○ How to tell if the baby is doing well
			  ○ Medical information specific to the baby's condition
			• Format
			  ○ Resource
			
			Support needs
			
			• Medical staff support
			  ○ Being able to contact about questions
			  ○ Building confidence
			• Familial support
				Limitations
				Variation in the time between discharge and the interviews could have influenced mothers' experiences. No fathers were interviewed.
				
				Other information
				The assessment of the quality of the study was performed using the CASP checklist for qualitative studies
				1. Was there a clear statement of the aims of the research? Yes
				2. Is a qualitative methodology appropriate? Yes
				3. Was the research design appropriate to address the aims of the research? Yes
				4. Was the recruitment

Study details	Participants	Methods	Themes	Comments
Aim of the study The aim of the study was to explore mothers' experiences in caring for preterm babies following discharge from the NICU. **Study dates** 2007-2008 **Source of funding** Bliss, UK	Medical needs postdischarge, n (%) Supplemental oxygen= 3 (30) **Inclusion criteria** Parent was fluent in English and participated in the larger RCT of parent involvement in infant comfort in the NICU. **Exclusion criteria** Parent less than 6 years of age, lack of fluency in English, documented psychological or psychiatric conditions. **Interventions** Not applicable	collected until thematic saturation was reached. **Data analysis** The first author transcribed the interviews verbatim. Transcripts were read twice to identify meaning units. Meaning units were then grouped into themes. Credibility, transferability, dependability and confirmability were achieved through various methods- a reflective diary, audio-recorder, auditing transcripts, and validation of results by the second author.		strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Can't tell (researchers did not state whether they critically examined their own role in the research) 7. Have ethical issues been taken into consideration? Can't tell (Insufficient details to explain whether ethical standards were maintained throughout study) 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary
Full citation	**Sample size** N=14	**Details**	**Results** Information needs	**Limitations**

Study details	Participants	Methods	Themes	Comments

Jackson, K., Ternestedt, B. M., Schollin, J., From alienation to familiarity: experiences of mothers and fathers of preterm infants, Journal of Advanced Nursing, 43, 120-9, 2003
 	
Ref Id
 	
445669
 	
Country/ies where the study was carried out
 	
Sweden
 	
Study type
Semi-structured interviews
 	
Aim of the study
The aim of the study was to assess how parents of preterm babies describe their experiences of parenthood during the baby's first 18 months
 	
Study dates
1999
	Characteristics
	Parents, n= 14
	Mothers, n (%)= 7 (50)
	Mother's age, years, median (range)= 32.5 (28-37)
	Father's age, years, median (range)= 32.5 (31-39)
	Babies, n= 8
	Male, n (%)= 5 (62.5)
	Birth weight, grams, median (range)= 1467.5 (660-2385)
	Gestational age, weeks, median (range)= 30 (25-34)
	Length of hospitalisation, days, median (range)= 49 (14-121)
	
	Inclusion criteria
	Babies were born at a gestational age ≤ 34 weeks without any congenital or chromosomal abnormalities, parents spoke Swedish and lived in the county. Babies were judged by a neonatologist at 1 week to have a good chance of survival.
	
	Exclusion criteria
	Not reported
		Sampling
		Not reported
		
		Setting
		Interviews 1 and 2 took place in the NICU, interviews 3 and 4 took place in the parents' homes
		
		Data collection
		Sets formed of the mother and father were considered a single unit. The majority of interviews were conducted with mothers and fathers together. Each interview built on the previous one. Interviews lasted 45-90 minutes and were audio-recorded and transcribed verbatim. Interviews took place at during different time points in the baby's development - 1-2 weeks after birth; at the time of discharge from the NICU; when the baby was 6 months old; and when the baby was 18 months old.
		
		Data analysis
		First all of the transcripts were read to gain an understanding of the content. The text was divided
			• Preparation
			  ○ Hands-on experience in the NICU
			
			Support needs
			
			• Medical staff support
			  ○ Feeling ready
			  ○ Trust and security
			• Family support
			• Other parents
				Parents were interviewed together which could have caused interference between narratives.
				
				Other information
				The assessment of the quality of the study was performed using the CASP checklist for qualitative studies
				1. Was there a clear statement of the aims of the research? Yes
				2. Is a qualitative methodology appropriate? Yes
				3. Was the research design appropriate to address the aims of the research? Yes
				4. Was the recruitment strategy appropriate to the aims of the research? Can't tell (recruitment strategy not reported)
				5. Was the data collected in a way that addressed the research issue? Yes
				6. Has the relationship between researcher and participants been adequately considered? Yes

Study details	Participants	Methods	Themes	Comments
Source of funding Not reported	**Interventions** Not applicable	into meaning units, which were transformed into a nursing perspective. Meaning units were condensed into 4 main themes which were then integrated to form a structural framework. The syntheses were validated by the second author and discrepancies were discussed until agreement was reached.		7. Have ethical issues been taken into consideration? Can't tell (insufficient evidence to tell whether ethical standards were maintained) 8. Was the data analysis sufficiently rigorous? Yes 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Full citation
 	
Jönsson, L, Fridlund, B, Parents' Conceptions of Participating in a Home Care Programme from NICU: A Qualitative Analysis, Vård i Norden, 23, 35-39, 2003
 	
Ref Id
 	
861172
 	
Country/ies where the study was carried out
 	
Sweden
	Sample size
	N=23
	
	Characteristics
	Parents, n=23
	Age, n (%) < 30= 11 (47.8)
	31-35= 7 (30.4)
	> 36= 5 (21.7)
	Female, n (%)= 17 (73.9)
	Twins, n (%)= 3 (13.0)
	
	Inclusion criteria
		Details
		Potential participants were first contacted by post and then by phone to confirm the interview. Parents who agreed to participate provided informed consent.
		
		Sampling
		Strategic sampling was used to select participants with varying ages, gender, profession, and additional children.
			Results
			Information needs
			
			• Format
			  ○ Personnel
			
			Support needs
			
			• Medical staff support
			  ○ Being able to contact about questions
			• Familial support
				Limitations
				Lack of generalisability to broader populations
				
				Other information
				
				The assessment of the quality of the study was performed using the CASP checklist for qualitative studies

Study details	Participants	Methods	Themes	Comments
Study type Semi-structured interviews **Aim of the study** The aim of the study was to describe parents' conceptions of participating in a home care programme provided by the NICU. **Study dates** 1999 **Source of funding** Not reported	Parents whose babies were cared for in a NICU in the southwestern part of Sweden **Exclusion criteria** Not reported **Interventions** The home care team visited families who had been discharged from the NICU to the family home.	**Setting** Parents' home or the hospital **Data collection** Interviews were audio-recorded and transcribed verbatim and lasted 30-60 minutes. The interview questions were developed by the study authors and were piloted on 2 participants. **Data analysis** Transcripts were first read several times to gain an understanding of the texts. Segments of text were meaning were isolated and compared with each other. These codes were combined to create the final coding framework. Data saturation was reached after 16 interviews.		1. Was there a clear statement of the aims of the research? Yes 2. Is a qualitative methodology appropriate? Yes 3. Was the research design appropriate to address the aims of the research? Yes 4. Was the recruitment strategy appropriate to the aims of the research? Yes 5. Was the data collected in a way that addressed the research issue? Yes 6. Has the relationship between researcher and participants been adequately considered? Yes 7. Have ethical issues been taken into consideration? Yes 8. Was the data analysis sufficiently rigorous? No (Researchers did not

Study details	Participants	Methods	Themes	Comments
				explain how the data presented were selected from the original sample to demonstrate the analysis process; insufficient data were presented to support the findings) 9. Is there a clear statement of findings? Yes 10. How valuable is the research? Researchers discuss the contribution the study makes to existing literature; and identify new areas where research is necessary

Appendix E – Forest plots

Forest plots for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

Not applicable for this review.

Forest plots for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

Not applicable for this review.

Appendix F – GRADE CERQual tables

GRADE CERQual tables for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

Table 5: Qualitative evidence profile: Theme 1. Preparing parents for the baby's daily care needs

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub theme 1: Mentally					
2 (Helder 2012; Hobbs 2017)	2 semi-structured interviews	2 studies conducted in different countries (the Netherlands, USA) among 28 critical care nurses and neonatology fellows responsible for preterm infants requiring respiratory support during discharge from the NICU reported that staff should address parents' fears and anxieties by giving helpful information and encouraging them to express their feelings while participating in the baby's care.	Methodological limitations	Moderate concerns[1,2]	Very low
			Relevance of findings	Moderate concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[4]	
Sub theme 2: Practically					
2 (Helder 2012; Hobbs 2017)	2 semi-structured interviews	2 studies conducted in different countries (the Netherlands, USA) among 28 critical care nurses and neonatology fellows responsible for preterm infants requiring respiratory support during discharge from the NICU reported that it is necessary to prepare parents for the responsibility of their baby's care by involving them in daily care activities in the NICU. Discharge plans should include information on routine newborn care, as well as information specific to their preterm baby's needs, such as calculating battery power or how to attend doctor's appointments with babies on medical technology.	Methodological limitations	Moderate concerns[1,2]	Very low
			Relevance of findings	Moderate concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[4]	

NICU: neonatal intensive care unit

[1]The confidence in the methodological quality was downgraded by 1 due to the study not clearly reporting the sampling method or relationship between the researcher and participants (Helder 2012)
[2]The confidence in the methodological quality was downgraded by 1 due to the study not clearly reporting the sampling method or relationship between the researcher and participants (Hobbs 2017)
[3]The confidence in the relevance of the evidence was downgraded by 1 due to a proportion of the babies not being preterm, having a congenital abnormality, or not requiring respiratory support (Hobbs 2017)
[4]The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.

Table 6: Qualitative evidence profile: Theme 2. Practical aspects

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub theme 1: Transportation					
2 (Helder 2012; Hobbs 2017)	2 semi-structured interviews	2 studies conducted in different countries (the Netherlands, USA) 28 among critical care nurses and neonatology fellows responsible for preterm infants requiring respiratory support during discharge from the NICU reported that nurses need to know the time of departure in order to coordinate the transfer and decrease parents' anxiety. It is also important for parents to learn how to travel with their technology-dependent preterm baby to facilitate mobility and attendance at appointments.	Methodological limitations	Moderate concerns[1,2]	Very low
			Relevance of findings	Moderate concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[4]	
Sub theme 2: Home set up					
2 (Helder 2012; Hobbs 2017)	2 semi-structured interviews	2 studies conducted in different countries (the Netherlands, USA) among 28 critical care nurses and neonatology fellows responsible for preterm infants requiring respiratory support during discharge from the NICU reported that parents should be informed of the requirements of the home prior discharge in order to provide them with enough time to make necessary conversions. Homes should be clean and quiet.	Methodological limitations	Moderate concerns[1,2]	Very low
			Relevance of findings	Minor concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[4]	

NICU: neonatal intensive care unit

[1]The confidence in the methodological quality was downgraded by 1 due to the study not clearly reporting the sampling method or relationship between the researcher and participants (Helder 2012)
[2]The confidence in the methodological quality was downgraded by 1 due to the study not clearly reporting the sampling method or relationship between the researcher and participants (Hobbs 2017)
[3]The confidence in the relevance of the evidence was downgraded by 1 due to a proportion of the babies not being preterm, having a congenital abnormality, or not requiring respiratory support (Hobbs 2017)
[4] The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.

Table 7: Qualitative evidence profile: Theme 3. Interpersonal aspects

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub theme 1: Normalising					
1 (Hobbs 2017)	1 semi-structured interview	1 study conducted in the USA among 10 neonatology fellows responsible for preterm	Methodological limitations	Moderate concerns[1]	Very low
			Relevance of findings	Moderate concerns[2]	

Study information			CERQual assessment of the evidence		
Number of studies	**Design**	**Description of theme or finding**	**Criteria**	**Assessment of Concerns**	**Overall Confidence**
		babies requiring respiratory support during discharge from the NICU reported that parents should be assisted in learning how to normalise daily life, for example, how to run errands or to secure childcare for medically complex babies. Efforts should also be made to ensure that home care routines permit time for parents to sleep and home nursing be made available to provide parents physical and emotional respite.	Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[3]	
Sub theme 2: Clear and simple communication with parents					
1 (Hobbs 2017)	1 semi-structured interview	1 study conducted in the USA among 10 neonatology fellows responsible for preterm babies requiring respiratory support during discharge from the NICU reported that clear communication throughout the discharge process so that parents can adequately care for the baby. The home nursing team should be identified in advance of the discharge date so as to avoid a rushed and chaotic discharge process. Follow-up appointments should be scheduled with parents and care instructions should avoid medical jargon and acknowledge the new care setting in the home.	Methodological limitations	Moderate concerns[1]	Very low
			Relevance of findings	Moderate concerns[2]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[3]	
1 (Hobbs 2017)	1 semi-structured interview	1 study conducted in the US among 10 neonatology fellows responsible for preterm babies requiring respiratory support during discharge from the NICU reported that staff from the NICU should account for family dynamics and should consider the role of extended family members during the NICU discharge process. Asking about the social environment is important for staff when creating the discharge plan so that home care routines are appropriate for the family's context.	Methodological limitations	Moderate concerns[1]	Very low
			Relevance of findings	Moderate concerns[2]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[3]	

NICU: neonatal intensive care unit

[1]The confidence in the methodological quality was downgraded by 1 due to the study not clearly reporting the sampling method or relationship between the researcher and participants, as well as (Hobbs 2017)
[2]The confidence in the relevance of the evidence was downgraded by 1 due to a proportion of the babies not being preterm, having a congenital abnormality, or not requiring respiratory support (Hobbs 2017)
[3] The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.

GRADE CERQual tables for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

Table 8: Qualitative evidence profile: Theme 1. NICU staff support

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub-theme 1: Being able to contact about questions					
5 (Burnham 2013; Dellemark-Blom 2016; Jonsson 2003; Lindberg 2009; Murdoch 2012)	5 semi-structured interviews	5 studies conducted in different countries (Canada; Sweden) among mothers and parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that having access to NICU staff, preferably those who cared for the baby, to ask questions or discuss concerns improved feelings of support and decreased feelings of abandonment.	Methodological limitations	Serious concerns[1,2]	Very low
			Relevance of findings	Moderate concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 2: Building confidence					
2 (Dellenmark-Blom 2016; Murdoch 2012)	2 semi-structured interviews	2 studies conducted in different countries (Canada; Sweden) among mothers and parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that NICU staff who provided confirmation and reassurance of the baby's health helped to build mothers' confidence in their caretaking abilities.	Methodological limitations	No concerns	Low
			Relevance of findings	Moderate concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[4]	
Sub theme 3: Feeling ready					
3 (Burnham 2013; Jackson 2003; Lindberg 2009)	3 semi-structured interviews	3 studies conducted in different countries (Canada; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that receiving positive feedback from NICU staff and participating in the decisions about the discharge enabled parents to feel ready.	Methodological limitations	Minor concerns[2]	High
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub-theme 4: Self care					
1 (Burnham 2013)	1 semi-structured interview	1 study conducted in Canada among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that NICU staff could remind them about the risk of postpartum depression and provide resources to provide more support.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Moderate concerns[4]	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub-theme 5: Trust and security					
5 (Burnham 2013; Dellenmark-Blom 2016; Helder 2012; Jackson 2003; Lindberg 2009)	5 semi-structured interviews	5 studies conducted in different countries (Canada; the Netherlands; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that remaining in contact with the NICU post-discharge helped them to feel secure. Having nurses who took the time to discuss questions and concerns while the baby was still in the NICU helped the parents to build a sense of trust and feel secure knowing that they could contact staff later on.	Methodological limitations	Minor concerns[2]	Low
			Relevance of findings	Moderate concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	

[1]*The confidence in the quality of the evidence was downgraded by 2 because researchers did not explain how the data presented were selected from the original sample to demonstrate the analysis process; insufficient data were presented to support the findings (Jonsson 2003)*
[2]*The confidence in the quality of the evidence was downgraded by 1 because researchers did not explain the recruitment strategy; did not explain whether they critically examined their own role in the research; or did not discuss methods to ensure credibility i.e. triangulation, participant validation (Lindberg 2009; Murdoch 2012)*
[3]*The confidence in the relevance of the findings was downgraded by 2 because a portion of the babies were born full-term, had a congenital malformation, or did not require respiratory support (Dellenmark-Blom 2016; Murdoch 2012)*
[4] *The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.*

Table 9: Qualitative evidence profile: Theme 2. Family support

Study information		Description of theme or finding	CERQual assessment of confidence in the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
3 (Jackson 2003; Jonsson 2003; Murdoch 2012)	3 semi-structured interviews	3 studies conducted in different countries (Canada; Sweden) among mothers and parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that receiving support from parents or siblings helped mothers to become confident in their caretaking abilities and to distribute the burden of caretaking and household tasks. Additionally, fathers described feeling guilty when they struggled to balance work and family life and wished that they could provide more support for the mothers.	Methodological limitations	Serious concerns[1,2]	Very low
			Relevance of findings	Moderate concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	

[1]*The confidence in the quality of the evidence was downgraded by 2 because researchers did not explain how the data presented were selected from the original sample to demonstrate the analysis process; insufficient data were presented to support the findings (Jonsson 2003)*
[2]*The confidence in the quality of the evidence was downgraded by 1 because researchers did not explain the recruitment strategy; did not explain whether they critically examined their own role in the research; or did not discuss methods to ensure credibility i.e. triangulation, participant validation (Murdoch 2012)*

[3]*The confidence in the relevance of the findings was downgraded by 2 because a portion of the babies were born full-term, had a congenital malformation, or did not require respiratory support (Dellenmark-Blom 2016; Murdoch 2012)*

Table 10: Qualitative evidence profile: Theme 3. Other parents

Study information		Description of theme or finding	CERQual assessment of confidence in the evidence		
Number of studies	Design		Criteria	Assessment of Concerns	Overall Confidence
1 (Jackson 2003)	1 semi-structured interview	1 study conducted in Sweden among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that mothers wanted to be in contact with other mothers of preterm babies whom they had met through parent education sessions organised by the NICU.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[1]	

[1] *The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.*

Information needs

Table 11: Qualitative evidence profile: Theme 1. Preparation

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	Design		Criteria	Assessment of Concerns	Overall Confidence
Sub theme 1: How to prepare the home					
1 (Burnham 2013)	Semi-structured interviews	1 study conducted in Canada among parents of preterm babies who are transitioning from neonatal unit while receiving respiratory support reported that parents would have liked a clear set of instructions about the specialised materials that needed to be bought ahead of time, such as thermometers, scales, and respiratory monitors, as well as changes that needed to be made to the home to accommodate equipment. Furthermore, safety instructions, such as limiting the number of visitors to the home should be communicated prior to discharge.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[1]	
Sub theme 2: Hands-on experience in the NICU					
2 (Burnham 2013; Jackson 2003)	2 semi-structured interviews	2 studies conducted in different countries (Canada; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that having the opportunity to care for the baby in	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[1]	

Study information		Description of theme or finding	CERQual assessment of the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
		a safe environment with the supervision of nurses and staying overnight in the NICU gave them an idea for what life would be like post-discharge and feel ready to take on the caregiving responsibilities.			
Sub theme 3: Transportation from the NICU					
1 (Helder 2012)	1 semi-structured interview	1 study conducted in the Netherlands among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that parents wanted a consistent policy on whether they could join their baby in the ambulance during transfer from the NICU.	Methodological limitations	Minor concerns[2]	Very low
			Relevance of findings	Moderate concerns[3]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[1]	

[1] *The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.*
[2]*The confidence in the quality of the evidence was downgraded by 1 due to studies not critically reflecting on the researchers' roles in the research and did not describe the sampling method (Helder 2012)*
[3]*The confidence in the relevance of the findings was downgraded by 2 because a portion of the babies were born full-term (Helder 2012)*

Table 12: Qualitative evidence profile: Theme 2. Routine care

Study information		Description of theme or finding	CERQual assessment of confidence in the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub-theme 1: How to tell if the baby is doing well					
3 (Burnham 2013; Dellenmark-Blom 2016; Murdoch 2012)	3 semi-structured interviews	3 studies conducted in different countries (Canada; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that learning about their baby's physiological needs, such as breathing patterns, recognising signs of illness was important for parents to feel prepared for discharge.	Methodological limitations	No concerns	Moderate
			Relevance of findings	Moderate concerns[1]	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub-theme 2: What to do if something goes wrong					
1 (Burnham 2013)	1 semi-structured interview	1 study conducted in Canada among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that parents wanted to know how to handle emergencies, for example if the baby stopped breathing. Courses such as infant cardiopulmonary resuscitation would enable parents to feel better equipped.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[2]	

Study information		Description of theme or finding	CERQual assessment of confidence in the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
Sub-theme 3: Medical information specific to the baby's condition					
2 (Burnham 2013; Murdoch 2012)	2 semi-structured interviews	2 studies conducted in Canada among mothers and parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that parents wanted information specific to their baby's health condition and about how to perform medical procedures at home.	Methodological limitations	No concerns	Low
			Relevance of findings	Moderate concerns[1]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[2]	
Sub-theme 4: Physiological needs					
1 (Burnham 2013)	1 semi-structured interview	1 study conducted in Canada among parents of preterm babies who are transitioning from neonatal unit while receiving respiratory support reported that parents wanted to know how to adjust routines from the NICU to use in the home. Knowing how to switch to on-demand feeding, how to know when volumes of feeding should be increased, and changes in breastfeeding patterns was important. Additionally, parents wanted to know how to position and swaddle babies when sleeping and what temperature the baby should be at.	Methodological limitations	No concerns	Low
			Relevance of findings	Moderate concerns[1]	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[2]	

[1]The confidence in the relevance of the findings was downgraded by 2 because a portion of the babies were born full-term, had a congenital malformation, or did not require respiratory support (Dellenmark-Blom 2016; Helder 2012; Murdoch 2012)
[2] The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.

Table 13: Qualitative evidence profile: Theme 3. Follow up

Study information		Description of theme or finding	CERQual assessment of confidence in the evidence		
Number of studies	**Design**		**Criteria**	**Assessment of Concerns**	**Overall Confidence**
1 (Burnham 2013)	1 semi-structured interview	1 study conducted in Canada among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that having a list of paediatricians to contact post-discharge, how to make follow-up appointments, if babies might experience developmental delays, and immunisations their child required.	Methodological limitations	No concerns	Moderate
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	Minor concerns[1]	

[1]The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.

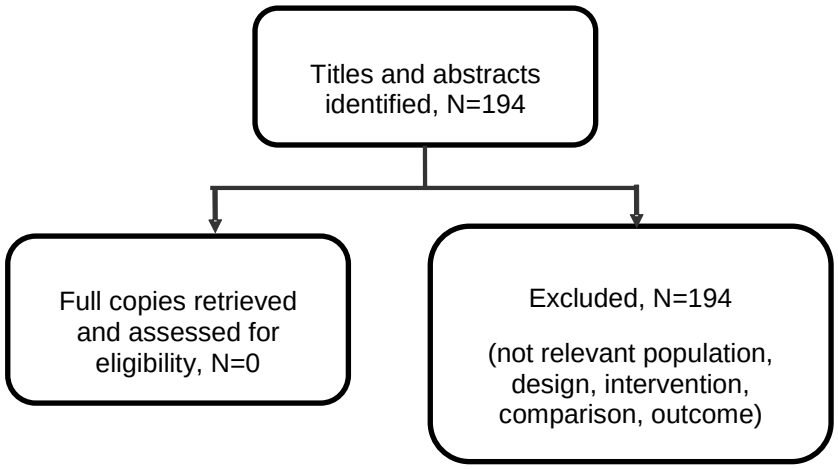
Table 14: Qualitative evidence profile: Theme 4. Format

Study information			CERQual assessment of confidence in the evidence		
Number of studies	Design	Description of theme or finding	Criteria	Assessment of Concerns	Overall Confidence
Sub theme 1: Timing					
1 (Burnham 2013)	1 semi-structured interview	1 study conducted in Canada among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that preparation should begin on admission with the opportunity to follow up and ask questions throughout the baby's stay in the NICU. However, some noted that parents might not be able to absorb information if it is given too soon after admission.	Methodological limitations	No concerns	Low
			Relevance of findings	No concerns	
			Coherence of findings	Moderate concerns[1]	
			Adequacy of evidence	Minor concerns[2]	
Sub theme 2: Resources					
3 (Burnham 2013; Helder 2012; Murdoch 2012)	3 semi-structured interviews	3 studies conducted in different countries (Canada; the Netherlands; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that regardless of format, resources should be up to date. Pamphlets on basic care at home, nurse-led group support and information sessions, online resources (links to websites or NICU parent networks), and books were mentioned as ideal ways to receive information.	Methodological limitations	Minor concerns[3]	Low
			Relevance of findings	Moderate concerns[4]	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	
Sub theme 3: Personnel					
2 (Burnham 2013; Jonsson 2003)	2 semi-structured interviews	2 studies conducted in different countries (Canada; Sweden) among parents of preterm babies who are transitioning from the neonatal unit while receiving respiratory support reported that parents preferred learning how to care for their baby from the nurse, but wished to speak with physicians about the baby's health status.	Methodological limitations	Moderate concerns[5]	Low
			Relevance of findings	No concerns	
			Coherence of findings	No concerns	
			Adequacy of evidence	No concerns	

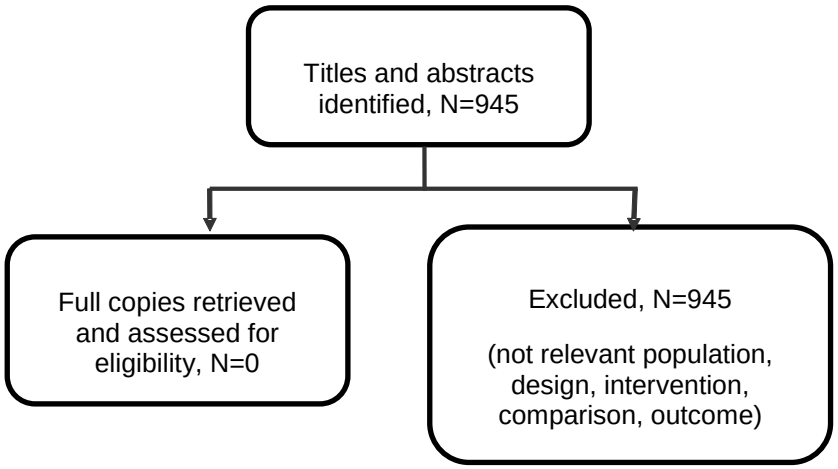
[1]*The confidence in the coherence of the findings was downgraded by 2 due to conflicting evidence (Burnham 2013)*
[2] *The confidence in the adequacy of the evidence was downgraded by 1 due to data saturation not being reached. Themes were under-developed and analysing further data would likely reveal new data and concepts.*
[3] *The confidence in the quality of the evidence was downgraded by 1 due to studies not critically reflecting on the researchers' roles in the research and did not describe the sampling method (Helder 2012)*
[4] *The confidence in the relevance of the findings was downgraded by 2 because a portion of the babies were born full-term, had a congenital malformation, or did not require respiratory support (Helder 2012; Murdoch 2012)*
[5]*The confidence in the quality of the evidence was downgraded by 2 because researchers did not explain how the data presented were selected from the original sample to demonstrate the analysis process; insufficient data were presented to support the findings (Jonsson 2003)*

Appendix G – Economic evidence study selection

Economic evidence study selection for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?



Economic evidence study selection for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?



Appendix H – Economic evidence table

Economic evidence table for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

No economic evidence was identified for this review.

Economic evidence table for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

No economic evidence was identified for this review.

Appendix I – Economic evidence profiles

Economic evidence profiles for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

No economic evidence was identified for this review.

Economic evidence profiles for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

No economic evidence was identified for this review.

Appendix J – Economic analysis

Economic analysis for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

No economic analysis was undertaken for this review.

Economic analysis for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

No economic analysis was undertaken for this review.

Appendix K – Excluded studies

Excluded studies for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

Clinical studies

Study	Reason for Exclusion
New strategy helps with discharging preemies, Discharge Planning Advisor, 2, 48-48, 2009	Conference abstract
Follow-up calls improve discharge instructions: contact helps with problems, reinforces opportunity, Hospital Case Management, 11, 108-109, 2003	Newsletter
Neonatal home program saves money, helps babies: NICU-experienced nurses manage babies' care, Hospital Home Health, 19, 67-71, 2002	Newsletter
Aloysius, Annie, Kharusi, Maryam, Winter, Robyn, Platonos, Karen, Banerjee, Jayanta, Deierl, Aniko, Support for families beyond discharge from the NICU, Journal of Neonatal Nursing, 24, 55-60, 2018	Study did not discuss babies with respiratory support
Annibale, D. J., Brown, M., Cox, T. H., Weiglein, C. A., Purohit, D., Discharge planning for very low birthweight infants, Journal - South Carolina Medical Association, 98, 145-54, 2002	Narrative review - no qualitative outcomes
Benavente Fernandez, I., Sanchez Redondo, M. D., Leante Castellanos, J. L., Perez Munuzuri, A., Rite Gracia, S., Ruiz Campillo, C. W., Sanz Lopez, E., Sanchez Luna, M., Hospital discharge criteria for very low birth weight newborns, Anales de Pediatria, 87, 54.e1-54.e8, 2017	Narrative review - no qualitative outcomes
Bowles, J. D., Jnah, A. J., Newberry, D. M., Hubbard, C. A., Roberston, T., Infants With Technology Dependence: Facilitating the Road to Home, Adv Neonatal CareAdvances in neonatal care : official journal of the National Association of Neonatal Nurses, 16, 424-429, 2016	Narrative review - no qualitative outcomes
Boykova, M., Transition From Hospital to Home in Parents of Preterm Infants: A Literature Review, The Journal of perinatal & neonatal nursing, 30, 327-348, 2016	Systematic review- studies assessed individually
Committee on, Fetus, Newborn,, Hospital discharge of the high-risk neonate, Pediatrics, 122, 1119-1126, 2008	Policy statement
Currie, G., Dosani, A., Premji, S. S., Reilly, S. M., Lodha, A. K., Young, M., Caring for late preterm infants: public health nurses' experiences, BMC NursBMC nursing, 17, 16, 2018	Did not discuss respiratory support
Dorling, J., Field, D., Follow up of infants following discharge from the neonatal unit: Structure and process, Early human development, 82, 151-156, 2006	Narrative review - no qualitative outcomes
Favero, Luciane, Mazza, Verônica de Azevedo, Lacerda, Maria Ribeiro, Experience of a nurse in transpersonal caring for families of neonates	Population not relevant - interviews with parents

Study	Reason for Exclusion
discharged from the intensive care unit, Acta Paulista de Enfermagem, 25, 490-496, 2012	
Fratantoni, K., Waters, D., Tuchman, L., Jiggetts, M., Soghier, L., Understanding the needs of families after NICU discharge to inform a peer support program, Developmental Medicine and Child Neurology, 58, 89-90, 2016	Conference abstract
Gambotto, S., Picca, M., The follow-up of preterm infant after discharge: Family pediatrician (FP) medical viewpoint, Italian Journal of Pediatrics. Conference: 71st Congress of the Italian Society of Pediatrics. Italy., 41, 2015	Did not discuss respiratory support
Goldenring, J. M., What to tell parents before they leave the hospital, Contemporary Pediatrics, 24, 52-59, 2007	Narrative review - no qualitative outcomes
Griffin, T., Abraham, M., Transition to home from the newborn intensive care unit: applying the principles of family-centered care to the discharge process, J Perinat Neonatal NursThe Journal of perinatal & neonatal nursing, 20, 243-9; quiz 250-1, 2006	Narrative review - no qualitative outcomes
Harrold,J., Schmidt,B., Evidence-based neonatology: Making a difference beyond discharge from the neonatal nursery, Current Opinion in Pediatrics, 14, 165-169, 2002	Randomised controlled trials - no qualitative outcomes
Hummel, P., Cronin, J., Home care of the high-risk infant, Advances in Neonatal Care, 4, 354-64, 2004	Narrative review - no qualitative outcomes
Ingram, J., Redshaw, M., Manns, S., Beasant, L., Johnson, D., Fleming, P., Pontin, D., "Giving us hope": Parent and neonatal staff views and expectations of a planned family-centred discharge process (Train-to-Home), Health ExpectationsHealth Expect, 20, 751-759, 2017	Did not discuss respiratory support
Ingram, J., Redshaw, M., Manns, S., et al.,, "Giving us hope": Parent and neonatal staff views and expectations of a planned family-centred discharge process (Train-to-Home), Health ExpectationsHealth Expect, 20, 751-759, 2017	Study did not discuss babies with respiratory support
Jefferies, A. L., Going home: Facilitating discharge of the preterm infant, Paediatrics and Child Health, 19, 31-42, 2014	Narrative review - no qualitative outcomes
Lucia, M. A., Mullaly, L. M., The discharge brunch: Reducing chaos and increasing smiles on the ob unit, Nursing for Women's Health, 13, 402-409, 2009	Not about safety needs
Miquel-Verges, F., Donohue, P. K., Boss, R. D., Discharge of Infants from NICU to Latino Families with Limited English Proficiency, Journal of immigrant and minority health, 13, 309-314, 2011	Study did not discuss babies with respiratory support
Murch, T. N., Smith, V. C., Supporting Families as They Transition Home, Newborn & Infant Nursing Reviews, 16, 298-302, 2016	Study did not discuss babies with respiratory support
Pados, B. F., Safe transition to home: preparing the near-term infant for discharge, Newborn & Infant Nursing Reviews, 7, 106-113, 2007	Literature review

Study	Reason for Exclusion
Pauline Voie, M., Tunby, J., Stromsvik, N., Collaboration challenges faced by nurses when premature infants are discharged, Nursing Children and Young PeopleNurs Child Young People, 30, 33-38, 2018	Did not discuss respiratory support
Purdy, I. B., Craig, J. W., Zeanah, P., NICU discharge planning and beyond: Recommendations for parent psychosocial support, Journal of Perinatology, 35, S24-S28, 2015	Narrative review - no qualitative outcomes
Raffray, M., Semenic, S., Osorio Galeano, S., Ochoa Marin, S. C., Barriers and facilitators to preparing families with premature infants for discharge home from the neonatal unit. Perceptions of health care providers, Investigacion y Educacion en Enfermeria, 32, 379-92, 2014	Non-OECD country- Colombia
Raines, D. A., SIMULATION as Part of DISCHARGE TEACHING for Parents of Infants in the Neonatal Intensive Care Unit, Mcn-the American Journal of Maternal-Child Nursing, 42, 95-107, 2017	Study did not discuss babies with requiring respiratory support
Ronan, Susan, Liberatos, Penny, Weingarten, Sarah, Wells, Princess, Garry, Jessica, O Brien, Kathryn, Parher-Bozzuto, Sarah, Schultz, Stacy L., Nevid, Tracy, Development of Home Educational Materials for Families of Preterm Infants, Neonatal Network, 34, 102-112, 2015	Study did not discuss babies requiring respiratory support
Scherf, R. F., Reid, K. W., Going home: what NICU nurses need to know about home care, Neonatal Network: the Journal of Neonatal Nursing, 25, 421-425, 2006	Narrative review - no qualitative outcomes
Schlittenhart, J. M., Smart, D., Miller, K., Severtson, B., Preparing Parents for NICU Discharge: An Evidence-Based Teaching Tool, Nursing for Women's Health, 15, 484-494, 2011	Study did not discuss babies with respiratory support
Schlittenhart, Jean M., Discharge Essentials- 'The NICU Experience: Going Home', JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing, 40, S28-S28, 2011	Poster presentation
Schuetz Haemmerli, N., Latal, B., Nelle, M., Stoffel, L., Cignacco, E., Transition to home (TTH) after preterm birth: Pilot testing of an advanced practice nurse (APN)-led new model of transitional care, European journal of pediatrics, 175 (11), 1854-1855, 2016	Conference abstract
Sherratt, A., Working within practice boundaries: developing a parent information leaflet in order to enhance the neonatal discharge examination, Journal of Neonatal Nursing, 7, 120-125, 2001	Conference abstract
Sims, D. C., Jacob, J., Mills, M. M., Fett, P. A., Novak, G., Evaluation and development of potentially better practices to improve the discharge process in the neonatal intensive care unit, Pediatrics, 118 Suppl 2, S115-23, 2006	Study did not discuss babies with respiratory support
Smith, V. C., Young, S., Pursley, D. M., McCormick, M. C., Zupancic, J. A., Are families prepared for	Quantitative design

Study	Reason for Exclusion
discharge from the NICU?, Journal of Perinatology, 29, 623-9, 2009	
Smith,V.C., Hwang,S.S., Dukhovny,D., Young,S., Pursley,D.M., Neonatal intensive care unit discharge preparation, family readiness and infant outcomes: Connecting the dots, Journal of Perinatology, 33, 415-421, 2013	Narrative review - no qualitative outcomes
Tamborelli, Geraldine, Welcome Aboard and Homeward Bound: The NICU Family's Journey for a Safe Voyage to Discharge, JOGNN: Journal of Obstetric, Gynecologic & Neonatal Nursing, 41, S36-S36, 2012	Conference abstract
Tearl, D. K., Cox, T. J., Hertzog, J. H., Hospital discharge of respiratory-technology-dependent children: Role of a dedicated respiratory care discharge coordinator, Respiratory Care, 51, 744-749, 2006	Quantitative design
Thorley, V., The Tenth Step of the BFHI: what midwives need to know about optimal support for mothers, post-discharge, Midwifery, 31, 829-833, 2015	Babies not preterm
Whyte, R. K., Neonatal management and safe discharge of late and moderate preterm infants, Seminars In Fetal & Neonatal MedicineSemin Fetal Neonatal Med, 17, 153-8, 2012	Narrative review - no qualitative outcomes
Whyte, R. K., Hilliard, R. I., Jefferies, A. L., Peliowski-Davidovich, A., Sorokan, S. T., Whyte, H. E. A., Safe discharge of the late preterm infant, Paediatrics and Child Health, 15, 655-660, 2010	Narrative review - no qualitative outcomes
Willis,V., Parenting preemies: a unique program for family support and education after NICU discharge, Advances in Neonatal Care, 8, 221-230, 2008	Narrative review - no qualitative outcomes
Woods, S., Riley, P., A role for community health care providers in neonatal follow-up, Paediatrics and Child Health, 11, 301-302, 2006	Editorial

OECD: Organisation for Economic Co-operation and Development

Economic studies

All economic studies were excluded at the initial title and abstract screening stage.

Excluded studies for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

Clinical studies

Study	Reason for Exclusion
How parents cope with the transition from the neonatal unit to home, Pract MidwifeThe practising midwife, 6, 34, 2003	Summary of Bissell 2003

Study	Reason for Exclusion
Certain factors can help prepare families to bring infants home from neonatal intensive care units, AHRQ Research Activities, 11-11, 2010	Summary of Smith 2009
Adama, E. A., Bayes, S., Sundin, D., Parents' experiences of caring for preterm infants after discharge with grandmothers as their main support, J Clin NursJournal of clinical nursing, 05, 05, 2017	Systematic review - studies assessed individually
Alderdice, F., Gargan, P., McCall, E., Franck, L., Online information for parents caring for their premature baby at home: A focus group study and systematic web search, Health Expectations, 30, 30, 2018	Study did not discuss babies with respiratory support
Aydon, L., Hauck, Y., Murdoch, J., Siu, D., Sharp, M., Transition from hospital to home: Parents' perception of their preparation and readiness for discharge with their preterm infant, Journal of Clinical Nursing, 27, 269-277, 2018	Study did not discuss babies with respiratory support
Bain, J., Findlay, A., Greig, C., Parents' perceptions of discharge planning in Scottish neonatal units: areas for improvement, Journal of Neonatal Nursing, 9, 110-115, 2003	Conference abstract
Bissell, G., Long, T., From the neonatal unit to home: how do parents adapt to life at home with their baby?, Journal of Neonatal Nursing, 9, 7-12, 2003	Conference abstract
Boonmee, J., Pickler, R. H., Transition of preterm infants from hospital to home, Neonatal Intensive Care, 18, 22-25, 2005	Conference abstract
Boykova, M., Life After Discharge: What Parents of Preterm Infants Say About Their Transition to Home, Newborn and Infant Nursing Reviews, 16, 58-65, 2016	Study did not discuss babies with respiratory support
Boykova, Marina, Transition from hospital to home in parents of preterm infants: A literature review, J Perinat Neonatal NursThe Journal of perinatal & neonatal nursing, 30, 327-348, 2016	Systematic review - studies assessed individually
Broedsgaard,A., Wagner,L., How to facilitate parents and their premature infant for the transition home, International Nursing Review, 52, 196-203, 2005	Did not discuss babies require respiratory support
Callen, J., Pinelli, J., Atkinson, S., Saigal, S., Qualitative analysis of barriers to breastfeeding in very-low-birthweight infants in the hospital and postdischarge, Advances in Neonatal Care, 5, 93-103, 2005	Study did not discuss babies requiring respiratory support
Cescutti-Butler, L., Eliciting parental views regarding early discharge to home care for premature infants, Infant, 5, 23-27, 2009	Conference abstract
Craig, Jenene Woods, The Neonatal Intensive Care Unit (NICU): Self-efficacy of caregiving and the lived experience of parents post-NICU discharge, Dissertation Abstracts International: Section B: The Sciences and Engineering, 76, No Pagination Specified, 2016	Dissertation
de Oliveira Dornasbach, Jéssica, Barbosa de Freitas, Hilda Maria, Santini Costenaro, Regina Gema, Rangel, Rosiane Filipin, Zamberlan, Claudia, Ilha, Silomar, NEONATAL INTENSIVE CARE: FEELING OF	Did not discuss babies requiring respiratory support

Study	Reason for Exclusion
PARENTS AFTER DISCHARGE OF THE CHILD, Journal of Nursing UFPE / Revista de Enfermagem UFPE, 8, 2660-2666, 2014	
de Souza Lima Marski, Bruna, Custodio, Natália, Porto de Abreu, Flávia Corrêa, Falleiros de Melo, Débora, Wernet, Monika, Hospital discharge of premature newborns: the father's experience, Revista brasileira de enfermagem, 69, 202-209, 2016	Study did not discuss babies with respiratory support
Discenza, D., NICU parents' top ten worries at discharge, Neonatal network : NN, 28, 202-203, 2009	Editorial
Ericson, Jenny, Flacking, Renée, Udo, Camilla, Mothers' experiences of a telephone based breastfeeding support intervention after discharge from neonatal intensive care units: a mixed-method study, International Breastfeeding JournalInt Breastfeed J, 12, 1-9, 2017	Study did not discuss babies with respiratory support
Flacking, Renee, Ewald, Uwe, Starrin, Bengt, "I wanted to do a good job": Experiences of 'becoming a mother' and breastfeeding in mothers of very preterm infants after discharge from a neonatal unit, Social Science & MedicineSoc Sci Med, 64, 2405-2416, 2007	Study did not discuss babies with respiratory support
Fratantoni, K., Waters, D., Tuchman, L., Jiggetts, M., Soghier, L., Understanding the needs of families after NICU discharge to inform a peer support program, Developmental Medicine and Child Neurology, 58, 89-90, 2016	Conference abstract
Galeano, M. D., Carvajal, B. V., Coping in Mothers of Premature Newborns After Hospital Discharge, Newborn & Infant Nursing Reviews, 16, 105-109, 2016	Non-OECD country- Colombia
Garel, M., Dardennes, M., Blondel, B., Mothers' psychological distress 1 year after very preterm childbirth. Results of the EPIPAGE qualitative study, Child: Care, Health & Development, 33, 137-43, 2007	Studies did not discuss babies requiring respiratory support
Garfield, C. F., Lee, Y., Kim, H. N., Paternal and Maternal Concerns for Their Very Low-Birth-Weight Infants Transitioning From the NICU to Home, Journal of Perinatal & Neonatal Nursing, 28, 305-312, 2014	Study did not discuss babies requiring respiratory support
Griffin, J. B., The experience of mothers of a preterm infant during the first month after the infant's hospital discharge, Ph.D., 180 p-180 p, 2008	Conference abstract
Griffin, Junyanee Boonmee, Pickler, Rita H., Hospital-to-home transition of mothers of preterm infants, MCN: The American Journal of Maternal/Child Nursing, 36, 252-257, 2011	Study did not discuss babies requiring respiratory support
Hemati, Z., Namnabati, M., Taleghani, F., Sadeghnia, A., Mothers' challenges after infants' discharge from neonatal intensive care unit: A qualitative study, Iranian Journal of Neonatology, 8, 31-36, 2017	Non-OECD country- Iran
Hutchinson, S. W., Parental experiences during their infants' transition process from a neonatal intensive care unit (NICU) to home, Ph.D., 143 p-143 p, 2002	Conference abstract
Hutchinson, S. W.,, Spillett, M. A.,, Cronin, M., Parentâ€ ™s experiences during their infantâ€ ™s	Study did not discuss babies requiring respiratory support

Study	Reason for Exclusion
transition from neonatal intensive care unit to home: a qualitative study, Qualitative Report, 17, 1-20, 2012	
Ingram, J., Redshaw, M., Manns, S., Beasant, L., Johnson, D., Fleming, P., Pontin, D., "Giving us hope": Parent and neonatal staff views and expectations of a planned family-centred discharge process (Train-to-Home), Health ExpectationsHealth Expect, 20, 751-759, 2017	Study did not discuss babies requiring respiratory support
Krowchuk, Heidi, TOWARD EVIDENCE-BASED PRACTICE. Paternal and Maternal Concerns for Their Very Low-Birth-Weight Infants Transitioning from the NICU to Home, MCN: The American Journal of Maternal Child Nursing, 40, 134-134, 2015	Editorial
Larsson, C., Wagstrom, U., Normann, E., Thernstrom Blomqvist, Y., Parents experiences of discharge readiness from a Swedish neonatal intensive care unit, Nursing OpenNurs, 4, 90-95, 2017	Study did not discuss babies requiring respiratory support
Lee, T. Y., Lee, T. T., Kuo, S. C., The experiences of mothers in breastfeeding their very low birth weight infants, Journal of Advanced Nursing, 65, 2523-2531, 2009	Did not discuss babies requiring respiratory support
Lima Alcântara, Kamille, de Souza Brito, Larissa Ludmila Monteiro, da Silva Costa, Deiziane Viana, Melo Façanha, Ana Paula, Barbosa Ximenes, Lorena, Melo Dodt, Regina Cláudia, FAMILY GUIDELINES NEEDED FOR A SAFE HOSPITAL OF THE PREMATURE NEWBORN: INTEGRATIVE REVIEW, Journal of Nursing UFPE / Revista de Enfermagem UFPE, 11, 645-655, 2017	Non-OECD country- Brazil
Lopez,G.L., Anderson,K.H., Feutchinger,J., Transition of premature infants from hospital to home life, Neonatal Network - Journal of Neonatal Nursing, 31, 207-214, 2012	Narrative review- studies assessed individually
Mai, D., Wagner, L., 'Home Early Program' -- experiences of parents to premature infants' one year after discharge, Nordic Journal of Nursing Research & Clinical Studies / Vård i Norden, 25, 60-63, 2005	Study did not discuss babies with respiratory support
Mancini, A., While, A., Discharge planning from a neonatal unit: an exploratory study of parents' views, Journal of Neonatal Nursing, 7, 59-62, 2001	Conference abstract
McInroy, A., Kritzinger, A., A single case study of the communication development of a high-risk neonate, from birth to discharge from a neonatal intensive care unit, The South African journal of communication disorders, Die Suid-Afrikaanse tydskrif vir Kommunikasieafwykings. 52, 25-35, 2005	Study did not discuss babies with respiratory support
Namnabati, M., Hemati, Z., Taleghani, F., Sadeghnia, A., Home-based care needs of preterm infants discharged early from the neonatal intensive care unit: A descriptive qualitative study, Iranian Journal of Neonatology, 8, 74-82, 2017	Non-OECD country- Iran
Nelson, V. S., Lewis, C. C., Ventilatory support: preparing for discharge...The Howard H. Steel Conference on Pediatric Spinal Cord Injury, Rancho	Narrative review

Study	Reason for Exclusion
Mirage, California, December 3-5, 1999, Topics in Spinal Cord Injury Rehabilitation, 6, 16-24, 2000	
Nilsson, I., Danbjorg, D. B., Aagaard, H., Strandberg-Larsen, K., Clemensen, J., Kronborg, H., Parental experiences of early postnatal discharge: A meta-synthesis, Midwifery, 31, 926-34, 2015	Study did not discuss babies with respiratory support
Osorio Galeano, Sandra Patricia, Ochoa Marín, Sandra Catalina, Semenic, Sonia, Preparing for post-discharge care of premature infants: Experiences of parents, Investigacion & Educacion en Enfermeria, 35, 100-108, 2017	Study did not discuss babies with respiratory support
Parker, Margaret, Kamholz, Karen, Brodsky, Dara, Zuckerman, Barry, Neonatal intensive care unit graduate home visit: A learning opportunity for pediatric interns, The Journal of Pediatrics, 161, 177-178, 2012	Quantitative design
Phillips-Pula, L., Pickler, R., McGrath, J. M., et al.,, Caring for a preterm infant at home: a mother's perspective, The Journal of Perinatal and Neonatal Nursing, 27, 335-344, 2013	Study did not discuss babies requiring respiratory support
Phillips-Pula, Lois, Caring for a Preterm Infant during the First Six Months Post NICU Discharge: A Mother's Perspective, Ph.D., 118 p-118 p, 2011	Dissertation
Premji, S. S., Currie, G., Reilly, S., Dosani, A., Oliver, L. M., Lodha, A. K., Young, M., A qualitative study: Mothers of late preterm infants relate their experiences of community based care, PLoS ONE, 12 (3) (no pagination), 2017	Only 10% of population had respiratory issues
Pritchard,M.A., Colditz,P.B., Beller,E.M., Parental experiences and preferences which influence subsequent use of post-discharge health services for children born very preterm, Journal of Paediatrics and Child Health, 44, 281-284, 2008	Study did not discuss babies requiring respiratory support
Quinn, Jenny, NICU Discharges: Parental and Nursing Perception of Readiness and Confidence, Advances in Neonatal Care (Lippincott Williams & Wilkins), 16, E10-E11, 2016	Conference abstract
Ra,J.S., Lim,J., Development and evaluation of a video discharge education program focusing on mother-infant interaction for mothers of premature infants, Journal of Korean Academy of Nursing, 42, 936-946, 2012	Quantitative design
Rabelo, M. Z. S., Chaves, E. M. C., Cardoso, M. V. L., Sherlock, M. S. M., Feelings and expectations of mothers of preterm babies at discharge, Acta Paulista de Enfermagem, 20, 333-337, 2007	Study did not discuss babies with respiratory support
Raffray, M., Semenic, S., Osorio Galeano, S., Ochoa Marin, S. C., Barriers and facilitators to preparing families with premature infants for discharge home from the neonatal unit. Perceptions of health care providers, Investigacion y Educacion en Enfermeria, 32, 379-92, 2014	Study did not discuss babies with respiratory support
Raines, D. A., Mothers' stressor as the day of discharge from th e nicu approaches, Advances in Neonatal Care, 13, 181-187, 2013	Quantitative design

Study	Reason for Exclusion
Reyna, B. A., Pickler, R. H., Thompson, A., A descriptive study of mothers' experiences feeding their preterm infants after discharge, Advances in Neonatal Care, 6, 333-40, 2006	Study did not discuss babies with respiratory support
Sankey, J. J., Brennan, S., Living with difference: caring for a premature baby at home, CollegianCollegian (Royal College of Nursing, Australia), 8, 10-8, 2001	Study did not discuss babies requiring respiratory support
Scherf, R. F., Reid, K. W., Going home: what NICU nurses need to know about home care, Neonatal Network: the Journal of Neonatal Nursing, 25, 421-425, 2006	Narrative review
Sneath, N., Discharge teaching in the NICU: are parents prepared? An integrative review of parents' perceptions, Neonatal network : NN, 28, 237-246, 2009	Literature review - studies assessed individually
Toral-López, Isabel, Fernández-Alcántara, Manuel, González-Carrión, Pilar, Cruz-Quintana, Francisco, Rivas-Campos, Antonio, Pérez-Marfil, Nieves, Needs Perceived by Parents of Preterm Infants: Integrating Care Into the Early Discharge Process, J Pediatr NursJournal of pediatric nursing, 31, e99-e108, 2016	Study did not discuss babies with respiratory support
Torok, L. S., The lived experience of receiving and caring for a technology-dependent infant in the home, Ph.D., 201 p-201 p, 2001	Dissertation
Turner,M., Winefield,H., Chur-Hansen,A., The emotional experiences and supports for parents with babies in a neonatal nursery, Advances in Neonatal Care, 13, 438-446, 2013	Study did not discuss babies requiring respiratory support
Viera, C. S., de Mello, D. F., de Oliveira, B. R. G., The follow-up of the family of the premature and low-birth-weight infant discharged from the NICU: a literature review, Online Brazilian Journal of Nursing, 7, 1-1, 2008	Non-OECD country- Brazil; Non-English language- Portuguese
White, Zachary, Gilstrap, Cristina, Hull, Jennifer, "Me against the world": Parental uncertainty management at home following neonatal intensive care unit discharge, Journal of Family Communication, 17, 105-116, 2017	Study did not discuss babies with respiratory support
Willis,V., Parenting preemies: a unique program for family support and education after NICU discharge, Advances in Neonatal Care, 8, 221-230, 2008	Did not discuss babies requiring respiratory support
Zamanzadeh, V., Namnabati, M., Valizadeh, L., Badiee, Z., Professional's Efforts to Simultaneously Discharge Infants and Mother from Neonatal Intensive Care Unit in Iran: A Qualitative Study, Journal of Caring SciencesJ Caring Sci, 2, 39-45, 2013	Non-OECD country- Iran

Economic studies

All economic studies were excluded at the initial title and abstract screening stage.

Appendix L – Research recommendations

Research recommendations for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

What is best practice around discharge planning for preterm babies on respiratory support?

Why this is important

For preterm babies on a neonatal unit, parents' involvement and responsibility for their baby's care increases over time to include, for example, giving medication or testing the placement of the feeding tube prior to giving milk. However, in many neonatal units, issues directly related to medical equipment, such as respiratory support, are often solely managed by the nursing and medical teams until the time of discharge. At present, it is generally agreed that best practice around discharge planning should include a partnership between hospital and community teams and follow-up planning and ensure that parents are able to confidently and safely use specialist equipment. However, there was insufficient evidence to identify specific elements that contribute to 'best practice' around discharge planning for preterm infants on respiratory support, thus necessitating further research. Evidence-based options into this area would facilitate and improve the safety of discharges, improve parental experience and may also reduce hospital costs by allowing earlier discharge and reducing readmission rates.

Table 15: Research recommendation rationale

Research question	'What is best practice around discharge planning for preterm babies on respiratory support?
Importance to 'patients' or the population	Parents need training in a timely manner regarding the safe use of specialist equipment prior to discharge to ensure that they feel empowered and skilled to care for their preterm baby on respiratory support at home. Early liaison between hospital and community agencies to improve communication, including arranging follow-up appointments and may facilitate earlier and safer discharge, which would be beneficial to the baby, family and may reduce hospital costs through lowering readmission rates.
Relevance to NICE guidance	Medium priority Two qualitative studies were identified from the NICE evidence review on the topic that highlighted important factors that contribute to safe discharge. However, the quality of the evidence was low due to methodological limitations affecting the risk of bias and adequacy of the findings. Future NICE guidance would benefit from more robust studies specifying which aspects contribute to best practice around discharge planning for preterm babies on respiratory support.
Relevance to the NHS	Earlier discharge of preterm babies on respiratory support from the neonatal unit will result in cost savings to the NHS, especially if there are fewer readmissions.
National priorities	Further research is needed to identify which factors most significantly contribute to best practice around discharge planning and which improve outcomes for babies, including morbidity and mortality.
Current evidence base	There is currently no strong evidence to identify the key factors which form best practice around discharge planning.
Equality	Currently, there is inconsistent practice around discharge planning for preterm babies on respiratory support. Babies and their families have an equal right to

Research question	'What is best practice around discharge planning for preterm babies on respiratory support?
	high quality, evidenced-based care practices which will improve the neonatal experience for the family and improve the baby's outcome.
Feasibility	Qualitative studies in this area are feasible. Randomised controlled trials and cohort studies are unlikely to be feasible to answer the qualitative nature of the research question.

Table 16: Research recommendation modified Population, context, outcome table

Criterion	Explanation
Population	Professionals in the multi-disciplinary team (MDT) caring for preterm babies who are being discharged home on respiratory support
Context	Minimum requirements that professionals caring for preterm babies requiring respiratory support find important in regard to the safe transition of the baby from the neonatal unit to a care setting (e.g. the home or hospice care) where the parents/carers, as opposed to healthcare professionals, are the main caregivers.
Outcome	Themes to be discussed in interviews or cohort studies: • Access to the MDT, including medical, specialist nursing and therapy teams, and psychological support • Community team involvement • Training or qualifications of the care provider that will be providing care post neonatal unit discharge • Named discharge co-ordinator or key worker, such as named consultant or nurse • Training and completion of competencies of parents • Medication administration • Support to facilitate the confidence of parents • Equipment provision • Care package funded • Suitable discharge destination environment • Housing • Electricity • Follow Up Care including discharge summaries
Study design	Qualitative – structured or semi-structured interviews with healthcare professionals or focus groups; single-centred or multi-centred approach

Research recommendations for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

No research recommendations were made for this review.

Appendix M – Qualitative quotes and excerpts

Qualitative quotes and excerpts for question 7.1 What factors are important when planning for the safe transition from the neonatal unit of a baby born preterm, requiring respiratory support?

Table 17: Theme 1: Social Support

Study ID	Evidence
Subtheme 1: Friends and Family	
Feeley 2013	"Instrumental support from family and friends, including meal preparation and assistance with household tasks and child care diminished demands, and this in turn provided time for fathers' involvement."
Feeley 2013	"'I have my in-laws… they are always there, whether it be for moral or practical support.'"
Smith 2012	"Parents commonly engaged family and friends for both pragmatic and emotional support… Friends and family members with medical backgrounds and/or NICU experience were particularly emotionally supportive, often serving as key information resources for many parents."
Smith 2012	"'The family support was also there. You know they were always coming and making sure that there was food in the house and helping to clean.'"
Ardal 2011	"Communication issues can arise as family members and friends struggle to provide support… mothers reported that they felt a lack of empathy for and understanding of the depth of their own anxiety, and of the reality of what their baby was going through"
Ardal 2011	"NICU mothers reported the added burden of educating and reassuring those in their support network who had no familiarity with the situation: 'Mothers who have gone through the same experience… are the only persons who understand us… and what we went through.'"
Smith 2012	"Family and friends who had little familiarity with the NICU were frequently perceived as unhelpful or even burdensome. These individuals often had concerns that reawakened parents' own worries."
Smith 2012	"'It was hard to talk to people that weren't in the immediate family, that weren't day-to-day following the babies…They had no experience with preemies and … you have to start from the beginning…That put a lot of stress on me.'"
Subtheme 2: Counselling	
Falck 2016	"Psychological and spiritual support provided by the interdisciplinary NICU was extremely valuable. Some mothers sought mental health services outside the hospital."
Falck 2016	"'I see a counselor because the whole birth process was overwhelming and traumatic. I think I have post-traumatic stress syndrome.'"
Feeley 2013	"Some fathers turned to online chat rooms dedicated to parents experiencing their infant's hospitalisation and used the concrete advice acquired there to guide their involvement."
Subtheme 3: Partners	
Falcking 2016	"Some mothers described feeling proud when watching their partners bond with their infant, as well as when they received encouragement and affirmation from their partners when providing care."
Falcking 2016	"'I cleaned him and changed him more confidently 2nd time… My partner was very impressed with me!!!'"

Feeley 2013	“Some couples developed a routine around caregiving activity, carving out a specific role for the father…Nonetheless, some mothers overtly discouraged fathers' involvement.”
Heinemann 2013	“The participants also described supporting each other as partners as extremely important. Some of the fathers described their strategy of pushing aside their own feelings in favour of the mother, who they considered in greater need of emotional support.”
MacDonald 2007	“When fathers were later observed in the NICU, they were actively engaged in the care of their infants to the extent that they could, and supported their spouse by assisting in diapering, taking temperatures, weighing and bathing the infants and helping to position the infants for feeding.”
MacDonald 2007	“These out-of-town families received extra support by being house at Easter Seal House, a non-profit housing unit located within blocks of the hospital, and in the case of one family being allowed to park their fifth-wheel motor home close to the hospital.”
Pohlman 2009	"'I don't need my wife to be upset. I know that after giving birth to a baby that a woman goes through the postpartum blues and it was real hard on her…Being at home every day and not being in the NICU and when she gets in the NICU she don't want to leave, which I don't want to either, but I know I have to. It's real hard.'"
Smith 2012	"'Every night when we left, [my partner and I] talked about it…I think that was good. It was constant communication. And so we weren't afraid to tell each other how we were feeling or what we were feeling. I think that kind of got us through it.'"
Smith 2012	“Being at home, parents were able to reconnect with each other and any older children.”
Smith 2012	“Partners also lessened material strains by dividing responsibilities related to work, household activities, and being in the NICU.”

Table 18: Theme 2: Staff Support

Study ID	Evidence
Subtheme 1: Facilitating Parents in Participating in Care	
Cescutti-Butler 2003	“Caring involves behaviour from staff that will facilitate parent involvement in their infant's care and work with parents as equal partners by sharing knowledge, values, responsibilities, outcomes and visions.”
Cescutti-Butler 2003	“Parents did not always feel they were equal partners in care…For instance, one of the fathers interviewed felt uncomfortable about obtaining information from his baby's charts, and would only look at the charts when the staff were not present.”
Gibbs 2016	“Becoming actively engaged in the provision of tube feeds assisted in achieving a sense of occupational engagement rather than being a spectator in their baby's care.”
Guillaume 2013	“Parents described their ability to have contact with the baby linked to the nurses' conduct, because it made the contact possible (or not) and pleasant (or not).”
Heinemann 2013	“Increased participation strengthened their self-esteem and parental role, which increased their motivation to be present.”
Heinemann 2013	“The staff had shown patience when parents did not feel ready for learning a procedure and had invited the parents to learn step by step and gradually take over most of the infant's care. The participants had felt encouraged by positive feedback on their performance of caregiving activities.”
Wigert 2014	“Not being allowed to participate in the ward round involving their child to hear some of the information that emerged was described as being deprived of their parental role.”
Wigert 2014	"'It was weird because it was my child who was lying there, so I wanted to know what they said'."

Study ID	Evidence
Wigert 2014	“When nurses provided information, encouragement to become involved and coaching, involvement was fostered.”
Subtheme 2: Facilitating Transition into Parenting Role	
Cescutti-Butler 2003	“Providing mothers and fathers with the opportunity to see and touch their infants in the delivery room or prior to transport may reduce stressful feelings. However, when this is not possible, minimizing the delay in time between birth and the first visit may be helpful for mothers.”
Cescutti-Butler 2003	“Once they were more familiar with the NICU, parents often felt they had little control of their own lives let alone of their baby, ‘The nurses like do more, it's my baby and I wanted to do more - they were doing stuff that I knew I could do and I would have liked to have been asked to do.’"
Cescutti-Butler 2003	“Having an element of control and feeling integrated will help parents acclimatize to the strange environment that having a baby in a NICU presents.”
Feeley 2013	“Fathers were involved in decision-making about the infant's care when staff shared information and provided the opportunity to ask questions.”
Feeley 2013	"'Yeah, getting involved in the decision process was easier at night. I could talk and ask questions.'"
Feeley 2013	“Fathers also described how nurses acted as role models. They carefully observed nurses providing care to their infant and learned how to do so, thus facilitating their involvement.”
Feeley 2013	“Explicit verbal encouragement from nursing staff or their partner helped fathers to begin to partake in caregiving activities.”
Feeley 2013	"'If the nurses were passing by and there was any improvement needed, then they would make suggestions.'"
Guillaume 2013	“After the delivery, many mothers reported having had to wait a day or two before being authorized to see their baby, for health reasons. The photograph of the baby and the NICU caregivers' visit to the mother's room were the two factors described as very useful for feeling closer to the child in these cases.”
Guillaume 2013	"'It was good to have this picture. I had two feelings….I was glad and sad at the same time…sad because she was premature.'"
Guillaume 2013	“Most parents described themselves as dependent on the staff to care for their baby and therefore necessarily subject to its authority”
Guillaume 2013	"'As we are in a place where everything is managed by others and we don't know, we have the impression that we have to ask for permission to touch him'"
Neu 1999	"'The nurses that we had really like me doing it [kangaroo care] because of her improved oxygen stats…They were really wonderful about me wanting to do it. I would have done it anyway, but it was easier because they were supportive and they made a fuss and thought it was wonderful that I did it.'"
Neu 1999	“The lack of appropriate support from the nursing staff also influenced the decision of some parents to discontinue skin-to-skin care.”
Smith 2012	“Participating in the care of their child was a critical coping strategy….Activities such as diaper changes and feeding provided concrete skills and a sense of "knowing" their child, which boosted self-confidence and combated insecurities about their role as parents.”
Smith 2012	"'It went from not holding her for a week to being able to hold her every couple days, and then slowly becoming a very active participant in her day. Just learning how to feed her, and hold her correctly, and bathe her.'"
Smith 2012	“Staff provided informal and formalized training on providing care, as well as opportunities for parents to practice. In addition, staff provided a welcoming environment and specific encouragement that parents needed to overcome anxieties about handling their child.”

Study ID	Evidence
Smith 2012	"'The nurses here don't care how much time I spend [trying] to change one diaper…they still let me try and …give me lots of tips…I learn a lot here.'"
Smith 2012	"One parent noted that it was helpful for staff to facilitate less intrusive visits by enforcing strict visiting rules with guests. Another said, the staff made note of a hospital Web site for NICU parents to provide standardized updates to friends and family, without having to interact individually."
Smith 2012	"'They told me about a website… where I could post pictures of [my baby] and give daily updates. Because one of the things that was very draining was people asking all the time, "how's the baby, how's the baby?"'"
Smith 2012	"Often what gave parents confidence to leave was their belief that the NICU staff had not only medical expertise but also affection for their child."
Wigert 2014	"The parents felt they were taken notice of when the staff responded to their need for information by listening attentively and calmly answering their questions… Parents also appreciated occasions when staff conveyed sensitivity to their need for consolation."
Wigert 2014	"'We noticed that they were keeping an eye on the situation…They were hanging around, they were there and started talking a bit and could tell if you wanted to talk.'"
Gibbs 2016	"Their engagement was focused on both reclaiming involvement in caregiving occupations they anticipated prior to the baby's birth and participating in alternative occupations that still allowed them to experience closeness with their infant."
Subtheme 3: Communication to Reduce Stress	
Falck 2016	"Transparent communication that provided information in a personalized and sensitive manner facilitated development of trusting relationships and minimized maternal anxiety"
Falck 2016	"Family meetings were valued as a forum for communication, shared decision making, and for parents to advocate for their child."
Falck 2016	"'Dr. *** was really good about keeping us up to speed each day…when we didn't see her in person she called us, she was wonderful about it…we like it up front, not being blindsided'"
Falck 2016	"'I need good communication. I need to feel like our beliefs, what we expect and what need, are being respected.'"
Flacking 2016	"Knowing how care was provided (e.g. procedures, technical devices, staff routines), what was expected of them as parents, and understanding the infant's signals enabled parents to relax and be in the present…The knowledge of their infant's medical status, gained through the communication with and by spending time with their infant, made parents feel more confidence in the parental role."
Flacking 2016	"'During the medical round when the doctor asked, how are your babies doing? I was very proud when I was able to tell them about my observations about the babies.'"
Gibbs 2016	"It was the intervention of a nurse that encouraged them to have hope for David's survival. Nell shared what the nurse said to them: 'It's ok to have hope for him… despite the medical circumstances, you're his parents and it's ok to have hope for him'"
Gibbs 2016	"The importance of receiving information about their infant's condition underpinned all communications that the parents undertook with NICU staff."
Gibbs 2016	"Facilitation was often twofold; it was about provision of information in a way that was accessible to the parents and the creation of opportunities for parents to participate in parenting occupations: 'It was good to be encouraged to do that [diaper changing] by the nurses, and for them even to show you how to do it.'"
Guillaume 2013	"Some fathers reported that the staff spoke to them less than the mother, which seemed normal or more rarely, frustrating in their role of father."

Study ID	Evidence
Guillaume 2013	“In the delivery room, mothers reported that they had needed explicit communication - words - about the baby's health, to be reassured that he was really alive: ‘As soon as I woke up, I asked: He's not dead? He's not dead?’”
Guillaume 2013	“Fathers and mothers both insisted on the need to warn them of changes such as intubation, changing the room, or placing a catheter.”
Guillaume 2013	“’If there is no problem with the examinations, the doctors don't come to tell you the results…If they tell us the results right away, whether they are good or bad, we know them and we can start to enjoy the child.’”
Guillaume 2013	“The telephone was described as a way of staying linked to the baby from home. Most parents reported feeling reassured by ritualized calls morning and evening…Some described calls more worrisome than reassuring, in cases where the phone rang repeatedly with no answer, and stressed the importance of always giving news, even succinctly.”
Guillaume 2013	“The fathers accompanied their child from the delivery room but frequently described an anxious wait at the ward entrance: ‘I would have liked it, when I arrived in the unit, for someone to come out and say to me, 'Your daughter is in good hands, we are going to take care of her,' just to reassure me that everything was all right.’”
Heinemann 2013	“The staff conveyed hope, without giving false expectations, which was perceived as essential.”
Holditch 2000	“The most helpful action was a nurse or other health care provider caring competently for the infant: ‘She thought maybe he was getting another little virus or something. She never said NEC. I don't think wanted to scare me until she had something to scare me about.’”
Pohlman 2009	“Fathers sometimes felt frustrated because the nurses did not fully inform them as to what they could or could not do with their infants during visits.”
Wigert 2014	“The parents felt that conversation with staff created the opportunity for a break from a reality that was difficult to live with.”
Wigert 2014	“The parents felt invited to communicate when the staff took the time to explain the child's care and treatment to them and invited them to participate in the child's care. The encouragement to care for the child strengthened parental bonding with the child.”
Wigert 2014	“’There is a communication together with us, [they] answer questions, provide support, tell us what we can do and what they will help with.’”
Wigert 2014	“The parents felt that they were dependent on communication with the staff to get information about their child and to get support from the staff to participate in their child's care.”
Wigert 2014	“’It would have felt good to have a review discussion there, what happened after the birth…because I have no idea of what happened there.’”
Wigert 2014	“The parents felt that, in their communication with the staff, they adapted to each member of staff's personality and their availability for conversation. They learned the different responsibilities of the various professionals and what roles they had in communicating with parents.”
Wigert 2014	“It could be difficult for parents to understand the doctor's information during the conversation, in which case the parents had to take the initiative to ask the nurse for an explanation of what had been said.”
Wigert 2014	“’Communication between the maternity ward and Neonatal could be improved. They had failed to schedule the hearing test. They didn't know if it was the maternity ward or Neonatal that booked it, so I had to check it myself.’”
Subtheme 4: Interpersonal Relationships	
Cescutti-Butler 2003	“Caring attributes: ‘Being genuinely concerned with you…Made you feel that your baby was important to them…The nurse would be there for you and give you a bit

Study ID	Evidence
	of confidence…You sort of got rapport with them, you feel more confident about asking questions'"
Cescutti-Butler 2003	"Relationships with families are central; skilled crisis intervention is needed, parents need assistance to interact with their very ill infants."
Cescutti-Butler 2003	"The mother's relationship with the nurse was the single most important influence on mothering…The nurse was a key focus maybe because they were a constant feature of their [the parents'] time in the NICU."
Gibbs 2016	"NICU staff were perceived as 'gatekeepers' to the infants, so this was an element of the NICU experience that parents took very seriously."
Gibbs 2016	"The development of collaborative parent-staff relationships that underpin the provision of family-centered care also provides the platform for supporting parents to participate in meaningful caregiving occupations."
Heinemann 2013	"Several participants expressed the need for confirmation of their concerns and for being treated with empathy…They appreciated that the staff fulfilled their role of being available for the parents and infants."
Holditch 2000	"'The nurses meant a lot to us. The nurses were real special. They would answer our questions and be straight with us. And say, 'Well, this could happen.' They were real supportive.'"
Holditch 2000	"'I think about the social worker a lot. I remember her face and the good words that she used…She talked to me a lot. She helped me a lot. She got me in contact with a lot of people who could be of help to me.'"
Jackson 2003	"In a sense the mothers were negotiating their role both with their infants with the hospital personnel as the infants were gaining strength and independence from medical equipment and as the nurses were encouraging and supporting their entry into complex feeding and nurturing routines."
Smith 2012	"Staff encouraged parent friendships by facilitating coffee hours or scrapbooking sessions as well as by arranging more structured relationships with graduate parents."
Smith 2012	"'I would have found [it] helpful… if I would've been put in touch with somebody whose child was in the exact same situation.'"
Wigert 2014	"The parents felt supported when they were met with compassion…It was comforting to meet the human being behind the professional role: 'The doctor listened, the doctor was also a person…she showed that she was also a fellow human being in the whole thing.'"
Subtheme 5: Continuity of Care	
Falck 2016	"For mothers, familiarity with nursing staff facilitated trust and confidence in nurses' abilities to care for their child. Assigning continuity attending facilitated smoother transitions and promoted maintenance of a consistent care plan."
Falck 2016	"'I wish there were consistency in care between doctors…I feel they switch way too often and they don't always know the baby. They have different opinions on what's the right thing to do, and it gets frustrating.'"
Gibbs 2016	"The inconsistency in advice received from the nursing staff was problematic and had the potential to erode trust between parents and staff."
Guillaume 2013	"Both parents also reported the supportive value of a visit by the paediatrician or the nurse to the mother's room, telling them about the baby's health."
Guillaume 2013	"'For 3 days I wasn't able to see my daughter. The doctors came to see me and the nurse also. I found that encouraging: I was very glad to get news about her.'"
MacDonald 2003	"Two of the mothers expressed frustration over conflicting approaches and contradictory advice around feeding strategies. Much of the frustration observed was the result of gaps between theory and practice as nurses and lactation consultants gave advice to the mothers who were struggling"

Study ID	Evidence
Pohlman 2009	"'Almost every day there's a different nurse in there… And I can tell just by how the nurse acts and everything whether she's gonna be gentle with her or whatever. Usually they are pretty rough and I just get nervous.'"
Pohlman 2009	"Building rapport, and therefore trust (what would seem to be an essential ingredient to feeling emotionally supported), was difficult when fathers saw a new face almost every day. The lack of consistent caregivers was on the minds of several fathers and they found this 'discomforting.'"
Pohlman 2009	"He felt that having consistent nurses also allowed him the opportunity to get to know the nurses "a little bit better…which made it easier to talk with them, makes it easier for you to think 'well, what can I ask this person'?'"
Wigert 2014	"Having a designated doctor and nurse contact in the NICU for their child provided continuity and felt important to the parents."
Wigert 2014	"'We had our contact nurses…it felt really nice because we could come to them with these extra requests.'"

Table 19: Theme 3: Parent-to-Parent Support

Study ID	Evidence
Subtheme 1: Shared Experiences	
Ardal 2011	"Mothers tended to talk to parent-buddies: 'I would talk to her [the buddy] in more detail rather than to other people because she has had the same experience.'"
Ardal 2011	"Sharing culture and language facilitates the process of communicating feelings: 'In the same language, we can understand everything; also, the feelings, I believe, are the same in the same culture.'"
Ardal 2011	"Sharing a culture fostered an understanding not only of the preterm birth experience but also of its cultural context."
Ardal 2011	"Buddies were able to normalize their experience and reassure them that their feelings were natural under the circumstances."
Ardal 2011	"The parent-buddies reduced the new mothers' experience of isolation related to both preterm birth and language and cultural differences."
Ardal 2011	"Judicious use of the buddy's own experience in response to the mother's concerns appeared to have a profound impact. One mother reported, after hearing a buddy's account of her son, who had been so sick and was now healthy: 'That changed my world completely. From there on, I was a person who could do it.'"
Smith 2012	"Engagement with other NICU parents was a coping strategy that several parents found helpful because it provided them with information and perspective. Graduate NICU parents whose children had faced similar medical issues were especially helpful."
Smith 2012	"'Sometimes you want to talk to someone who's been there, who's experiencing the exact same thing.'"
Smith 2012	"'You're a member of a club and no one likes to be a member of that club, and no one likes to talk about it. And all of a sudden (sic) when people start to share it, you don't feel so alone in it. And I, I think it's just really helpful, and I think it's really hard to be the first one to kind of share or to break through that wall, but once you do it's really supportive.'"
Gibbs 2016	"The fostering of relationships with other parents seemed to stem from the mutuality of parent experiences… This support was highly valued by parents, and the shared camaraderie with other parents was a noticeable loss once their infants were discharged."
Subtheme 2: Observational Learning	

Study ID	Evidence
Feeley 2013	“In the two open-spaced NICUs where this study took place, fathers saw other parents holding or diapering their infants, and this led to the realisation that involvement was possible and permitted.”

Table 20: Theme 4: Hospital Environment

Study ID	Evidence
Subtheme 1: Need for Privacy	
Falck 2016	“Physical space limited the ability of mothers to feel comfortable expressing emotions…despite use of screens to partition the infant's space. In addition, participants emphasized that this lack of privacy impacted confidential communication with families.”
Falck 2016	"’It was touch and go, and we weren't sure if she was going to make it, so I am sobbing and everybody is walking by.’"
Falck 2016	"’It would be helpful to be presented with a choice...can we step outside to talk about this… it's good to have that option so the whole NICU doesn't hear what's going on with your kid.’"
Flacking 2016	“Parents in Sweden and Finland highlighted the importance of feeling and being a family when alone with their infant. This was facilitated when parents had their own room on the NICU which they could bring the infant into: ‘Yesterday, it was also a wonderful moment when the father came and we were allowed to be alone in the room, as a family, without nurses or other parents.’"
Heinemann 2013	“It became more complicated to take turns in performing KMC, as the parent who was not providing KMC had no private space to get some rest.”
Jackson 2003	“The mothers wanted privacy and wished to be with the baby in a private area.”
Neu 1999	"’To take off her clothes and mine wasn't anything I could do at the hospital. I'm not that modest, but I would have been right in the middle of that room!'"
Neu 1999	Conversely parents who discontinued skn-to-skin holding in the hospital were quite cognizant of a sterile, noisy, busy, or crowded environment, inadequate privacy, loss of control, and lack of nursing support that precluded a gratifying skin-to-skin experience.
Neu 1999	"It seemed hard to do because everything was so rush, rush in there."
Subtheme 2: Friendly, Homelike Environments	
Feeley 2013	“Fathers felt that because the appearance of the NICU did not resemble the home environment, this deterred their involvement.”
Feeley 2013	“One father thought that this was particularly important in the step-down unit and explained, 'More space and more chairs and nice décor - there is a bit of soul would help.'"
Feeley 2013	“Open visiting policies allowed fathers unlimited access to the NICU. As one father noted, 'I can come here whenever I want - 24 hours.'"
Heinemann 2013	“Parents who had the opportunity to stay overnight in a family room in the NICU felt that it simplified their life and made it possible to perform KMC for large parts of the day by taking turns.”
Heinemann 2013	“Several parents attributed difficulties of being present during nights to a high level of illumination and the noise from alarms and staff chatting in loud voices.”
Subtheme 3: Feelings of Security or Insecurity	
Falck 2016	“Re: open room design - Mothers described a feeling of safety, comfort, and security provided by the proximity of multiple caregivers in the room at all times”
Falck 2016	"’The NICU is not a privacy place…I don't want it closed off because he is so unpredictable…some days I need to look across the room and say, "Hey, what is going on with him?’"

Study ID	Evidence
Feeley 2013	“One father described how the 'tubes' and 'wires' made him reluctant to provide care for his infant, stating 'I was always afraid, you know… I tried once, she started desaturating and the nurse said "Let me take her from your arms.”"
Holditch 2000	“Sometimes, the appearance of the entire NICU - equipment, infants, and families - overwhelmed the mothers ‘The first time that their monitors went off, it terrified me! But the staff there was really good about explaining what was going on.’"
Holditch 2000	“Medical complications could further impair the appearance of the infant: ‘When he was in the ICU, they had him paralyzed then. He just wasn't moving then, because he had the respirator on. They don't look like real babies when they're paralyzed. Almost like they're dead.’"
Guillaume 2013	“To be at ease with their child, the parents reported that they needed to understand the environment: ‘The more I know, the more I am reassured. What I want to know are the upper and lower limits, because I watch the monitor and I have the impression I understand.’"
Subtheme 4: Participating in care	
Gibbs 2016	“The NICU environment has a significant impact on participation in parenting occupations… The presence of lines and the types of respiratory equipment limited how much of their infant they could actually see.”
Gibbs 2016	“The incubator served to reinforce the critical nature of their infant's condition and placed significant limitations on their involvement in providing nurturing for their infant.”
Gibbs 2016	"’Sometimes you'd feel like you were just sitting there watching everybody do everything for him.’"
Gibbs 2016	“The various policies and unwritten ground rules, also shaped parents' experiences, including visiting restrictions imposed during infection outbreaks, the ability to engage in skin-to-skin contact based on the infant's respiratory support needs, and the exclusion of parents from the unit during ward rounds”
Flacking 2016	“For many parents, holding the infant and/or being skin-to-skin was the first time they felt their infant was theirs… By being physically close the parent-infant bond was strengthened.”
Flacking 2016	“Doing simple and ordinary parenting tasks made them feel that the infant was theirs; changing diapers, putting on clothes and washing and bathing their infant were significant events.”
Flacking 2016	“Some parents also specifically referred to how their increasing involvement in caretaking duties had had a simultaneous influence on their growing sense of commitment and connection.”
Flacking 2016	"’During the following days, the commitment and connection strengthened, especially when I got to spend all three nights at the neonatal unit next to my baby although he was on a monitor.’"
MacDonald 2003	“Mothers whose infants were on respirators or C-PAP mentioned the difficulty of accessing infants for skin-to-skin cuddles and in seeing their infant's face. The monitors and monitoring devices made the babies less accessible and the routines more challenging.”

Table 21: Theme 5: Employment Support

Study ID	Evidence
Financial Support	
Feeley 2013	“Paternity or other types of employment leaves allowed for greater presence, contributing to greater involvement.”
Feeley 2013	"’When my company gave me two weeks off, I was here Monday to Friday’"

Study ID	Evidence
Jackson 2003	“Four of the fathers were on parental leave during the hospitalization and were able to participate in the care of the infants. However, others had problems getting time off from work, which depended to a great extent on the attitudes of their employers.”

Qualitative quotes and excerpts for question 7.2 What are the support and information needs of parents and carers of preterm babies who are transitioning from the neonatal unit while receiving ongoing respiratory support?

Support Needs

Table 22: Theme 1: NICU staff support

Study ID	Evidence
Subtheme 1: Being able to contact about questions	
Burnham 2013	“Contact with the NICU postdischarge was helpful during the transition home. One mother explained that, if she had questions or concerns, ‘it would be useful to speak to somebody who actually took care of [my baby].’”
Dellenmark-Blom 2016	“Providing opportunities for telephone availability and regular but successively fewer home visits, the PNS reinforced feelings of not having been abandoned after discharge from NICU.”
Jonsson 2003	“Having accessibility- In this conception the parents described the accessibility to the home care team, usually by telephone. The scope ranged from a passive to an active contact.”
Lindberg 2009	“Parents expressed that they still had a lot of thoughts and questions after discharge, so it could have provided vital support to still have this access and thereafter decide when to return it (video conferencing equipment)”
Lindberg 2009	“Another advantage was that parents could talk together with a number of staff at the same time; much like a group conversation, something that is not possible by telephone.”
Lindberg 2009	“Further on, a condition for the set up was that staff’s reserved time for the meeting, at least the first days after they came back home.”
Murdoch 2012	“Mothers expressed apprehension about being the sole infant caregiver at home and questioned whether they could manage without medical support.”
Subtheme 2: Building confidence	
Dellenmark-Blom 2016	“Parents thus needed the PNS for confirmation that their infant is healthy and for reassurance that they are performing well as parents”
Dellenmark-Blom 2016	“Parents encountering the same nurse in both the NICU and NHC setting believed this further helped the processing of memories from the NICU period because the nurse had interacted with them in several contexts and knew their journey”
Murdoch 2012	“Health professionals provided reassurance regarding infant health and gave mothers confidence in their caretaking abilities.”
Subtheme 3: Feeling ready	
Burnham 2013	“Positive feedback from the NICU staff also enhanced parental readiness for discharge.”
Jackson 2003	“The mothers did not feel prepared for the baby’s discharge from the hospital and for their new responsibility, and felt insecure about caring for the baby. This was especially true for those with the smallest infants.”

Study ID	Evidence
Jackson 2003	“Fathers did not feel prepared to bring the infant home from the hospital, and did not feel that they had taken part in the decision about discharge.”
Lindberg 2009	“… parents felt the need to feel ready to return home instead of being sent home with the infant too early.”
Subtheme 4: Self care	
Burnham 2013	“Parents also reported a need to be reminded of the ever-present risk of postpartum depression (PPD) for parents.”
Subtheme 5: Trust and security	
Burnham 2013	“Parents felt more secure when HCPs they came into contact with postdischarge had a complete health history of their infant.”
Dellenmark-Blom 2016	“Parents’ sense of security was anchored by the PNS (Paediatric Nursing Specialist) providing both time and opportunity to calmly discuss new questions and concerns that invariably arise on return to the family home.”
Dellenmark-Blom 2016	“Parents believed that parenthood was facilitated by the emotional understanding and educational support provided by the PNS (Paediatric Nursing Specialist)”
Helder 2012	“A slow development of parents’ trust during the stay in the NICU, their sense of being betrayed by a sudden and unwanted transfer, and a rebuilding of confidence during the stay in the SCN.”
Jackson 2003	“One mother, who still worried about the baby’s breathing, did not feel she got adequate support and changed to a different nurse.”
Jackson 2003	“Mothers of the smallest infants remained in frequent contact with the neonatal ward as well as with the CHS, which made them feel secure.”
Lindberg 2009	“Knowing that they can contact staff- Parents expressed feelings of security just by having this access, which was the most essential for them, regardless of how often they actually used the equipment (video conferencing)”
Lindberg 2009	“They felt secure knowing that the staff could, by both listening to and seeing them and their infant, easily make an appraisal of the situation.”

Table 23: Theme 2: Familial support

Study ID	Evidence
Murdoch 2012	“Family support during the transition from hospital to home helped the mothers build confidence in their caretaking abilities. Families helped by distributing competing responsibilities and allowing the mother to focus on caring for her infant.”
Jackson 2003	“The fathers described feeling guilty because they could not participate in caring for the baby or supporting the mother as much as they wanted.”
Jackson 2003	“All the descriptions reflected a struggle to find a balance between work and family life.”
Jonsson 2003	“The scope ranged from received to perceived support. ‘We have got very good support from our parents and our siblings.’"

Table 24: Theme 3: Other parents

Study ID	Evidence
Jackson 2003	“Most of the women expressed a need for contact with mothers in the same situation, whom they had met in parent education sessions arranged by the CHS.”

Information needs

Table 25: Theme 1: Preparation

Study ID	Evidence
Subtheme 1: How to prepare the home	
Burnham 2013	"Questions remained about whether any specialized supplies or equipment were needed for a preterm infant…: what size diapers and bottle nipples to purchase, what type of thermometer to use, and whether adaptations to the car seat are required to accommodate a preterm infant. Several parents thought that providing this information early on in the infant's hospitalization would be helpful, allowing time to locate and purchase the items that were not necessarily readily available."
Burnham 2013	"Several post-discharge parents were not aware that they should limit the amount of visitors in their home or that their infant should not be taken out in public right away and would have liked to have this information before discharge."
Subtheme 2: Hands-on experience in the NICU	
Burnham 2013	"The need for hands-on experience for parents to feel ready for discharge. Parents recounted how experiences such as taking on their infant's care in the safe environment of the NICU were paramount in increasing their readiness for discharge."
Burnham 2013	"When performing a skill for the first time, parents preferred to have the nurse demonstrate before trying themselves under the nurse's supervision."
Burnham 2013	"Staying overnight in the parent room and taking on full caregiving responsibility of their infant helped parents get a sense of what life might look like at home. Encountering unanticipated situations while in the NICU was also seen as helpful."
Burnham 2013	"Cues from the NICU environment such as their infant's bed location in the unit and how staff spoke about their infant also affected parents' perceptions of their infant's readiness for discharge."
Burnham 2013	"Parents appreciated when efforts were made to simulate the home environment in the NICU."
Burnham 2013	"Interventions that provide parents with a better sense of what life at home might look like, such as taking the infant off of all monitors and switching the infant to on-demand feeding were seen as helpful steps in the transition from NICU to home."
Jackson 2003	"They [the fathers] missed the practical guidance at the hospital and said they would have liked to have had more direct supervision during the hospital stay: 'Coming home was very strange. I felt insecure, and in fact it felt like this was our first baby.'"
Subtheme 3: Transportation from NICU	
Helder 2012	"Parents regretted the lack of consistent policy on joining their infant in the ambulance"

Table 26: Theme 2: Routine care

Study ID	Evidence
Subtheme 1: Physiological needs	
Burnham 2013	"Infant feeding in particular was a topic parents wanted information about during the hospitalization as well as at home."
Burnham 2013	"How to schedule feedings at home; how to coordinate twins on the same feeding schedule at home; how to switch to on-demand feeding; is it normal for a baby to eat more at home; how to know when the volume of feedings should be increased; Changes to expect in a baby's breastfeeding behavior as he/she develops"
Burnham 2013	"Several parents did not know how they would be able to ensure that their infants were meeting their daily caloric needs and maintaining their weight at home. This concern was especially prevalent for breastfed infants."

Study ID	Evidence
Burnham 2013	“Which routes should be used and what are the acceptable ranges? How often should a baby's temperature be taken at home? What type of thermometer to buy. How warm should a baby's room be? How should a baby be dressed?”
Burnham 2013	“The infant's sleeping arrangements was also a topic that raised many questions.”
Burnham 2013	“Where should a baby sleep? Should a baby be positioned on a 30 degree-34 angle while sleeping? How many blankets should be used? How to swaddle a baby. What to do if a baby will not sleep.”
Subtheme 2: How to tell if baby is doing well	
Burnham 2013	“Parents wanted to know what physiological markers could be observed at home to ensure their infant was healthy. Parents questioned if they should purchase equipment such as scales and respiratory monitors to continue monitoring their infant at home.”
Burnham 2013	“Preterm infants’ breathing patterns were a concern for several parents, particularly for those whose infant had respiratory complications.”
Burnham 2013	“Preparing for unexpected events was a key topic parents required information about to enhance their readiness for discharge.”
Burnham 2013	“Recognizing signs of illness was also identified by parents as important to prepare for discharge.”
Dellenmark-Blom 2016	“The adjustment to routines that differed from those learnt in the NICU is, at first, difficult.”
Murdoch 2012	“Mothers commonly expressed apprehension that their infants would die under their care at home, and about possible negative sequelae of prematurity or illnesses.”
Subtheme 3: What to do if something goes wrong	
Burnham 2013	“Parents wanted information about what to do if their infant’s health status was compromised at home. Specific concerns ranged from emergency situations (e.g., infant stops breathing) to less urgent problems (e.g., infant has a cold, is constipated, or has diarrhoea).”
Burnham 2013	“Some parents felt strongly that an infant cardiopulmonary resuscitation course should be part of discharge preparation to be better equipped to handle an emergency situation.”
Subtheme 4: Medical information specific to baby's condition	
Burnham 2013	“Parents wanted information specific to their infant’s health condition and preferred speaking directly with HCPs.”
Murdoch 2012	“Three of nine mothers had infants requiring daily medical procedures. These mothers expressed concerns about performing the procedures at home.”

Table 27: Theme 3: Follow up

Study ID	Evidence
Burnham 2013	“Information about postdischarge follow-up was important to help parents feel ready for discharge. Parents whose infant met the age and weight criteria to be followed by the in-hospital follow-up clinic wanted to know how to make an appointment, how many visits there would be, and the duration of follow-up.”
Burnham 2013	“Immunizations, including information about the vaccine as well as scheduling, was a topic parents wanted more information about before discharge in order to make the appointments.”
Burnham 2013	“List of pediatricians to contact while their infant was still hospitalized”
Burnham 2013	“Concerns about potential risks the infant could face in the future were common… Parents wanted to know what they could expect after leaving the

Study ID	Evidence
	NICU and if their infant would be delayed in reaching developmental milestones."

Table 28: Theme 4: Format

Study ID	Evidence
Subtheme 1: Timing	
Burnham 2013	"Some parents felt that preparation should begin on admission; others felt that a few days to one week before discharge would be adequate and providing it earlier would be useless because 'that information is going to get lost anyway.' Most parents agreed that waiting until the day of discharge was too late."
Burnham 2013	"For many parents, receiving information once was sufficient; however, having the opportunity to follow up and ask questions was essential"
Subtheme 2: Resource	
Helder 2012	"Most parents had only received limited information from NICU nurses orally and from an (outdated) photo book and felt '… unprepared for what to expect.'"
Murdoch 2012	"Mothers obtained information and gained knowledge from numerous external resources, which provided guidance on care and health of their infants. Many mothers described using books on infant development."
Murdoch 2012	"Six suggested pamphlets on basic care of infants at home; two proposed help with transport for infants on supplemental oxygen; three suggested a few more nights with full infant responsibility before discharge; and five suggested a support group for mothers postdischarge."
Burnham 2013	"Face-to-face conversation was a favored method of receiving information because it allowed parents to ask questions and clarify elements they did not understand. Informal conversations with nurses at the infant's bedside were also valuable means of receiving information. Written material was suggested by some parents but only to supplement information already discussed in person. Parents suggested that books about premature infants should be stored in the NICU to facilitate access to information while visiting their infant."
Burnham 2013	"The CNS-led group support and information sessions for parents offered at the NICU were another preferred means of acquiring information."
Burnham 2013	"Online resources (e.g., website, NICU parent network) were also suggested methods of providing information."
Subtheme 3: Personnel	
Burnham 2013	"Nurses were seen as the ideal HCPs to help parents prepare for discharge, since they 'are the ones who take care of the baby, they know better than everyone else.' Parents wanted more information from the physicians about their infant's health status."
Burnham 2013	"The CNS-led group (Clinical Nurse Specialist) support and information sessions for parents offered at the NICU were another preferred means of acquiring information."
Jonsson 2003	"It was important to the parents to have access to the knowledge and advice of the healthcare professionals at the hospital and to the practical experiences of their relatives."