

Neonatal parenteral nutrition

[I] Information and support

NICE guideline tbc

Evidence reviews

September 2019

Draft for Consultation

These evidence reviews were developed by the National Guideline Alliance which is part of 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.

Local commissioners and/or providers have a responsibility to enable the guideline to be applied when individual health professionals and their patients or service users wish to use it. They should do so in the context of local and national priorities for funding and developing services, and in light of their duties to have due regard to the need to eliminate unlawful discrimination, to advance equality of opportunity and to reduce health inequalities. Nothing in this guideline should be interpreted in a way that would be inconsistent with compliance with those duties.

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ISBN:

Contents

Information and support	6
Review question	6
Introduction	6
Summary of the protocol	6
Clinical evidence	7
Summary of clinical studies included in the evidence review	7
Quality assessment of clinical studies included in the evidence review	8
Economic evidence	8
Summary of studies included in the economic evidence review.....	8
Economic model.....	8
Clinical evidence statements	8
Economic evidence statements	8
Research recommendations.....	8
The committee’s discussion of the evidence.....	8
Appendices	11
Appendix A – Review protocol.....	11
Review protocol for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?	11
Appendix B – Literature search strategies	16
Literature search strategy for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?	16
Appendix C – Clinical evidence study selection	22
Clinical evidence study selection for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?.....	22
Appendix D – Clinical evidence tables	23
Clinical evidence tables for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?	23
Appendix E – Forest plots.....	24
Clinical evidence forest plots for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?	24
Appendix F – GRADE tables	25
Clinical evidence GRADE tables for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?.....	25
Appendix G – Economic evidence study selection.....	26
Economic evidence study selection for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?.....	26

Appendix H – Economic evidence tables.....	27
Economic evidence tables for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?	27
Appendix I – Economic evidence profiles	28
Economic evidence profiles for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?	28
Appendix J – Economic analysis	29
Economic analysis for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?	29
Appendix K – Excluded studies	30
Excluded studies for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?	30
Clinical studies	30
Economic studies	30
Appendix L – Research recommendations	31
Research recommendation for review question: What are the most effective methods of information provision about PN and what information and support do parents or carers perceive as useful?	31

1 Information and support

2 Review question

3 What are the most effective methods of information provision about parenteral nutrition, and
4 what information and support about this do parents or carers perceive as useful?

5 Introduction

6 Having a baby on a neonatal unit can be a stressful and challenging time for parents or
7 carers, but information and support can help parents or carers understand the purpose of
8 parenteral nutrition (PN), provide them with relevant information about any risks; and ensure
9 that the administration of PN doesn't have a negative impact on their opportunities to handle
10 and care for their baby.

11 There is variation between neonatal units in the current provision of information to parents
12 and carers about PN. It is important to determine what information is provided and how
13 useful this information is for the parent or carer to ensure guidance on best practice can be
14 given.

15 Summary of the protocol

16 See Table 1 for a summary of the mixed method protocol: Population, Intervention,
17 Comparison and Outcome (PICO - quantitative), and Population, Interest and Context (PICO
18 – qualitative) characteristics of this review.

19 **Table 1: Summary of protocol (PICO table)**

Population	Quantitative: <ul style="list-style-type: none">• Parents or carers of babies receiving PN Qualitative <ul style="list-style-type: none">• Parents or carers of babies receiving PN• Health-care professionals working in neonatal parenteral nutrition
Intervention/Interest	Quantitative: <p>Provision of support to the parents or carers of babies on PN</p> <p>(For example, an information leaflet on PN, or web-based support programme (RCT data)).</p> Qualitative interest: <p>Studies addressing parents or carers views and experience of information provision and support needs</p> <p>OR</p> <p>Studies addressing the views of health care professionals on available and required information and support for parents or carers</p>
Comparator/Context	Quantitative comparisons: <p>An alternative provision of information support (for example, no provision of information).</p>

	(For example, no leaflet, or no web-based support (RCT data only)).
	Qualitative context Information and support for parents or carers in the context of neonatal parenteral nutrition
Outcomes	Critical Quantitative: <ul style="list-style-type: none">• Satisfaction of parent or carer (to cover satisfaction with the service provided, and/or the information available)• Awareness of support services Qualitative Themes: <ul style="list-style-type: none">• Satisfaction with care,• Worry/anxiety• Access: to support, to the baby, to logistical support (for example, help with travel),• Transition from PN to EN,• Benefits and harms of PN, parental recall. Important (quantitative): <ul style="list-style-type: none">• Uptake of services• Anxiety• Information content• Parental recall information

1 *EN: enteral nutrition; PN: parenteral nutrition; RCT: randomised controlled trial.*

2 For further details see the full review protocol in appendix A.

3 **Clinical evidence**

4 **Included studies**

5 A systematic review of the literature was conducted but no studies were identified which
6 were applicable to this review question.

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

9 **Excluded studies**

10 Studies not included in this review are listed, and reasons for their exclusions are provided in
11 appendix K.

12 **Summary of clinical studies included in the evidence review**

13 No studies were identified which were applicable to this review question.

1 Quality assessment of clinical studies included in the evidence review

2 No studies were identified which were applicable to this review question.

3 Economic evidence

4 Included studies

5 A systematic review of the economic literature was conducted but no economic studies were
6 identified which were applicable to this review question. A single economic search was
7 undertaken for all topics included in the scope of this guideline. Please see supplementary
8 material D for details.

9 Excluded studies

10 No studies were identified which were applicable to this review question.

11 Summary of studies included in the economic evidence review

12 No economic evaluations were identified which were applicable to this review question.

13 Economic model

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

16 Clinical evidence statements

17 No studies were identified which were applicable to this review question.

18 Economic evidence statements

19 No economic evidence was identified which was applicable to this review question.

20 Research recommendations

21 What are the information and support needs of parents or carers with babies on parenteral
22 nutrition?

23 The committee's discussion of the evidence

24 Interpreting the evidence

25 *The outcomes that matter most*

26 The committee agreed that the critical outcomes for this review should include satisfaction of
27 the parent or carer, and their awareness of available information and support services. These
28 were agreed as critical outcomes because the provision of information in this context
29 supports the parent or carer to feel involved in their baby's care. It is also crucial that if this
30 support is available, it is perceived by parents (and also the healthcare professional) to be
31 helpful and that it meets their needs. Therefore qualitative outcomes (summarised as themes
32 emerging from evidence) were also considered to be critical to enable shared decision

1 making and the provision of support tailored to the needs of parents of babies receiving PN.
2 It was anticipated that such themes may include levels of anxiety, uptake of support, and
3 recall of information.

4 ***The quality of the evidence***

5 No clinical evidence was identified for this review

6 ***Benefits and harms***

7 No clinical evidence was identified for this review; therefore, the committee used their
8 experience and informal consensus to make the recommendations. The committee
9 acknowledged that there is generally a lack of specific information for parents and carers
10 whose babies are receiving PN. Furthermore no evidence into how information and support
11 may help these parents or carers was found and the committee agreed that determining what
12 parents and carers find useful should be a research priority

13 The committee discussed how the content and extent of information that parents and carers
14 want to receive will likely depend on the individuals themselves, and so the committee do not
15 consider it appropriate to be too prescriptive about the provision of information. It is important
16 that healthcare providers work collaboratively with the parents or carers, allowing them to ask
17 questions and to feel involved in decision making where possible. The committee recognised
18 that this is an emotional and stressful time for parents and therefore tailoring information to
19 each individual is important. This should take into account the needs of parents and carers,
20 wishes and preferences, and their individual circumstances. The information should also be
21 up to date, and available in a variety of formats. The committee agree this would help to build
22 rapport and trust between parents or carers and healthcare professionals.

23 The committee noted that the details of the content of PN may not be the most important
24 thing on the mind of parents and carers. The parents and carers may be more concerned
25 about the impact its use has on whether they can hold their baby and how long their baby
26 may be in hospital. Therefore the committee members agreed the information should be
27 about the role, risks and benefits of PN in relation to the overall baby's well-being. This could
28 include a number of factors such: why PN is needed (i.e. in ensuring the babies nutritional
29 needs are met); what it involves and how this will impact on the baby's care (both clinically in
30 terms of placing catheters and blood monitoring but also practically in terms of how parents
31 and carers can handle their child), the likely duration; how the baby will transition to enteral
32 feeds (including bottle or breast feeding); and any potential long term consequences.
33 Information on PN may need to be part of a package of information regarding care of the
34 baby when in the neonatal intensive care unit.

35 The committee noted that many units will have an "admissions" booklet. However, these do
36 not generally include much information specific to PN. The committee believe these
37 recommendations will ensure written information is provided which does include this in
38 future. The committee agreed parents and carers may want information in different formats,
39 being provided with both verbal and written information should ensure people with different
40 learning styles can all benefit from provision of information and support.

41 Based on their experience, the committee also noted that provision of information and
42 support is an iterative process and that there are changing needs of the baby as well as new
43 support needs of parents or carers that may emerge during the baby's time on PN. The
44 committee also acknowledged that the needs of parents and carers may change with time,
45 for example they may want concise simple information initially, with more detail at a later
46 date. The committee therefore agreed that the healthcare provider should make time to

1 provide regular opportunities for the parents or carers to ask questions so that they continue
2 to feel supported.

3 Having identified the lack of evidence, the committee agreed that there is a need for further
4 research in this area because having a baby in a neonatal unit is a stressful and difficult time
5 for parents and carers. Information and support can help parents manage these
6 circumstances and help them feel involved and part of the care of their baby which can
7 improve outcomes. They therefore made a research recommendation to address this topic.

8 **Cost effectiveness and resource use**

9 There was no economic evidence on the cost-effectiveness of information provision to
10 parents and carers of preterm babies requiring PN. The committee discussed various
11 formats of information provision including leaflets, verbal, web-based, apps, etc. The
12 committee noted that there would be minimal costs associated with implementing these
13 recommendations, including costs in terms of the time needed to prepare and share such
14 information.

15 The committee explained that there may be a small sub-group of babies who are on PN for a
16 very long time and information needs may be different in such cases. The committee
17 explained that keeping parents or carers up to date are integral parts of most services and
18 providing such supplementary advice on PN would have only modest resource implications,
19 if any, which are justifiable as these principles and factors are deemed essential in ensuring
20 the success of care of preterm babies on PN (i.e. care, holding, risks/benefits, transition to
21 enteral feeding).

22 Overall, the information provision has the potential to facilitate parents' involvement in care,
23 minimise parental anxiety and make the interactions with the medical staff more efficient and
24 would represent a cost effective use of NHS resources.

25 **Other factors the committee took into account**

26 The committee expressed concern that there does not appear to be any good quality
27 information which is specific to parents or carers whose babies are receiving PN. Some
28 online resources provide general information about PN such as [Bliss](#) (an organisation
29 supporting parents or carers of premature babies), and the committee were aware of [online](#)
30 [information](#) from the Great Ormond Street hospital for children NHS foundation trust.
31 However, the committee discussed that these leaflets and online resources are generally
32 very broad and not specific enough and do not currently cover all the issues that the
33 committee recommended for discussion.

34 The committee also highlighted equality considerations, such as those related to people
35 whose first language is not English or people with difficulties understanding detailed
36 information. The committee agreed it was important to follow the principles (including needs
37 for interpreters) about communication and shared decision making, are outlined in the NICE
38 guideline on [patient experience in adult NHS services](#). They therefore cross-referred to this
39 guideline.

40 The committee also discussed that there is a currently a NICE guideline in progress that
41 addresses '[Babies', children and young people's experience of healthcare](#)'. This guideline is
42 expected to be published in April 2021 and therefore the committee could not cross-
43 reference to this. They were aware that progress of this guideline can be followed at the
44 provided hyperlink and future updates most likely would cross-reference to it.

1 Appendices

2 Appendix A – Review protocol

3 Review protocol for review question: What are the most effective methods of information provision about PN and what 4 information and support do parents or carers perceive as useful?

5 Table 2: Review protocol for parenteral nutrition in neonates: Information and support

Field (based on PRISMA-P)	Content
Review question	What are the most effective methods of information provision about PN, and what information and support about this do parents or carers perceive as useful?
Type of review question	Mixed quantitative and qualitative methods review
Objective of the review	To review how parents of babies on PN are provided with information and to review the views and experiences of parents or carers of babies receiving PN, determining what information was provided and how useful this was for the parent.
Eligibility criteria – population/disease/condition/issue/domain	<p>Quantitative</p> <ul style="list-style-type: none"> • Parents or carers of babies receiving PN <p>Qualitative</p> <ul style="list-style-type: none"> • Parents or carers of babies receiving PN • Health-care professionals working in neonatal parenteral nutrition
Eligibility criteria – intervention(s)/exposure(s)/prognostic factor(s)	<p>Quantitative:</p> <p>Provision of support to the parents or carers of babies on PN (For example an information leaflet on PN, or web-based support programme (RCT data))</p> <p>Qualitative interest:</p> <p>Studies addressing parents or carers views and experience of information provision and support needs in the context of neonatal parenteral nutrition. OR Studies addressing the views of health care professionals on available and required information and support for parents or carers in the context of neonatal parenteral nutrition.</p>
Eligibility criteria – comparator(s)/control or reference (gold) standard	<p>Quantitative:</p> <p>An alternative provision of information support (for example no provision of information (for example no leaflet, or no web-based support (RCT data only))</p>

Field (based on <u>PRISMA-P</u>)	Content
Outcomes and prioritisation	<p>Critical</p> <p>Quantitative</p> <ul style="list-style-type: none"> • Satisfaction of parent or carer (to cover satisfaction with the service provided, and/or the information available) • Awareness of support services <p>Qualitative Themes:</p> <ul style="list-style-type: none"> • Satisfaction with care, • Worry/anxiety • Access: to support, to the baby, to logistical support (for example, help with travel), • Transition from PN to EN, • Benefits and harms of PN, parental recall <p>Themes of the experiences and perceptions in the qualitative part of this review will be extracted from the primary studies, but may include some of the following: Satisfaction with care, worry, access to support, access to the baby (and how this may alter if the baby is on PN), access to logistical support (for example help with travel), transition from PN to EN, benefits and harms of PN, parental recall.</p> <p>Important (quantitative)</p> <ul style="list-style-type: none"> • Uptake of services • Anxiety • Information content • Parental recall of information
Eligibility criteria – study design	<p>Systematic reviews of qualitative reviews</p> <p>Systematic reviews of RCTs</p> <p>Primary qualitative reviews</p> <p>Survey studies with qualitative data</p> <p>RCTs</p> <p>Comparative cohort study</p>

Field (based on PRISMA-P)	Content
Other inclusion exclusion criteria	No sample size restriction No date restriction Commentaries, editorials, policy and guidance, conference abstracts
Proposed sensitivity/sub-group analysis, or meta-regression	Stratified analysis What factors enhance parents or carers satisfaction What enhances access to information What frequency and content of information to parents or cares want to receive Where evidence exists, consideration will be given to the specific needs of population subgroups: Critically ill babies or those requiring surgery (for example, inotropic support, therapeutic hypothermia or fluid restriction) Possible equality considerations: Mothers aged 17 or below Parents or carers whose first language is not English Parents or carers who have learning difficulties Socio-economic status Older mothers (>35 years)
Selection process – duplicate screening/selection/analysis	Sifting, data extraction, appraisal of methodological quality and GRADE assessment will be performed by the systematic reviewer. Quality control will be performed by the senior systematic reviewer. A random sample of the references will be sifted by a second reviewer. This sample size will be 10% of the total, or 100 studies if the search identifies fewer than 1000 studies. All disagreements will be resolved by discussion between the two reviewers. The senior systematic reviewer or guideline lead will act as arbiter where necessary.
Data management (software)	Pair-wise meta-analysis, if possible, will be performed using Cochrane Review Manager (RevMan5). 'GRADEpro' will be used to assess the quality of evidence for each outcome. Low income countries will be downgraded for indirectness. NGA STAR software will be used for generating bibliographies/citations, study sifting, data extraction and recording quality assessment using checklists (ROBIS (systematic reviews and meta-analyses), Cochrane risk of bias tool (RCTs)).
Information sources – databases and dates	Sources to be searched: Medline, Medline In-Process, CCTR, CDSR, DARE, HTA, Embase. Limits (e.g. date, study design): All study designs. Apply standard animal/non-English language filters. No date limit.

Field (based on <u>PRISMA-P</u>)	Content
	Supplementary search techniques: No supplementary search techniques were used. See appendix B for full strategies.
Identify if an update	This is not an update
Author contacts	Developer: The National Guideline Alliance https://www.nice.org.uk/guidance/indevelopment/gid-ng10037
Highlight if amendment to previous protocol	For details please see section 4.5 of Developing NICE guidelines: the manual 2014.
Search strategy – for one database	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 appendix B.
Methods for assessing bias at outcome/study level	Standard study checklists were used to critically appraise individual studies. For details please see section 6.2 of Developing NICE guidelines: the manual The risk of bias across all available evidence was evaluated for each outcome using an adaptation of the 'Grading of Recommendations Assessment, Development and Evaluation (GRADE) toolbox' developed by the international GRADE working group http://www.gradeworkinggroup.org/
Criteria for quantitative synthesis (where suitable)	For details please see section 6.4 of Developing NICE guidelines: the manual 2014.
Methods for analysis – combining studies and exploring (in)consistency	For details of the methods please see supplementary material C.
Meta-bias assessment – publication bias, selective reporting bias	For details please see section 6.2 of Developing NICE guidelines: the manual 2014.
Assessment of confidence in cumulative evidence	For details please see sections 6.4 and 9.1 of Developing NICE guidelines: the manual 2014.
Rationale/context – Current management	For details please see the introduction to the evidence review.

Field (based on <u>PRISMA-P</u>)	Content
Describe contributions of authors and guarantor	A multidisciplinary committee developed the guideline. The committee was convened by the National Guideline Alliance (NGA) and chaired by Joe Fawke (Consultant Neonatologist and Honorary Senior Lecturer, University Hospitals Leicester NHS Trust), in line with section 3 of Developing NICE guidelines: the manual 2014. 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 of the methods please see supplementary material C.
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	This review is not registered with PROSPERO.

- 1 CDSR: Cochrane Database of Systematic Reviews; CCTR: Cochrane Controlled Trials Register; DARE: Database of Abstracts of Reviews of Effects; EN: enteral nutrition;
2 GRADE: Grading of Recommendations Assessment, Development and Evaluation; HTA: Health Technology Assessment; NGA: National Guideline Alliance; NIHR: National
3 Institute for Health Research; NHS: National health service; NICE: National Institute for Health and Care Excellence; PN: parenteral nutrition; PRISMA-P: preferred reporting
4 items for systematic review and meta-analysis protocols; PROSPERO: International prospective register of systematic reviews; RCT: randomised controlled trial; RoB: risk of
5 bias; ROBIS: risk of bias in systematic reviews.

1 Appendix B – Literature search strategies

2 Literature search strategy for review question: What are the most effective
3 methods of information provision about PN and what information and support
4 do parents or carers perceive as useful?

5 Databases: Medline; Medline Epub Ahead of Print; and Medline In-Process & Other
6 Non-Indexed Citations

#	Searches
1	INFANT, NEWBORN/
2	(neonat\$ or newborn\$ or new-born\$ or baby or babies).ti,ab.
3	PREMATURE BIRTH/
4	((preterm\$ or pre-term\$ or prematur\$ or pre-matur\$) adj5 (birth? or born)).ab,ti.
5	exp INFANT, PREMATURE/
6	((preterm\$ or pre-term\$ or prematur\$ or pre-matur\$) adj5 infan\$).ti,ab.
7	(pre#mie? or premie or premies).ti,ab.
8	exp INFANT, LOW BIRTH WEIGHT/
9	(low adj3 birth adj3 weigh\$ adj5 infan\$).ti,ab.
10	((LBW or VLBW) adj5 infan\$).ti,ab.
11	INTENSIVE CARE, NEONATAL/
12	INTENSIVE CARE UNITS, NEONATAL/
13	NICU?.ti,ab.
14	or/1-13
15	PARENTERAL NUTRITION/
16	PARENTERAL NUTRITION, TOTAL/
17	PARENTERAL NUTRITION SOLUTIONS/
18	ADMINISTRATION, INTRAVENOUS/ and (nutrition\$ or feed\$ or fed\$).ti,ab.
19	INFUSIONS, INTRAVENOUS/ and (nutrition\$ or feed\$ or fed\$).ti,ab.
20	CATHETERIZATION, CENTRAL VENOUS/ and (nutrition\$ or feed\$ or fed\$).ti,ab.
21	exp CATHETERIZATION, PERIPHERAL/ and (nutrition\$ or feed\$ or fed\$).ti,ab.
22	((parenteral\$ or intravenous\$ or intra-venous\$ or IV or venous\$ or infusion?) adj3 (nutrition\$ or feed\$ or fed\$)).ti,ab.
23	((peripheral\$ or central\$) adj3 line? adj3 (nutrition\$ or feed\$ or fed\$)).ti,ab.
24	(catheter\$ adj3 (nutrition\$ or feed\$ or fed\$)).ti,ab.
25	(drip? adj3 (nutrition\$ or feed\$ or fed\$)).ti,ab.
26	or/15-25
27	FAMILY/
28	GRANDPARENTS/
29	exp PARENTS/
30	CAREGIVERS/
31	(famil\$ or parent? or parental or father\$ or mother\$ or grandparent\$ or grandfather\$ or grandmother\$ or carer\$ or caregiver\$).ti,ab.
32	or/27-31
33	exp HEALTH PERSONNEL/
34	(professional? OR personnel or doctor? or physician? or general practitioner? or GP? or nurse? or AHP? or pharmacist? or dietician? or neonatologist? or p?ediatrician?).ti,ab.
35	or/33-34
36	COUNSELING/
37	DIRECTIVE COUNSELING/
38	exp EDUCATION/
39	HEALTH EDUCATION/
40	exp COMMUNICATION/
41	exp CONSUMER HEALTH INFORMATION/
42	PATIENT EDUCATION AS TOPIC/
43	INFORMATION SEEKING BEHAVIOR/
44	POSTERS AS TOPIC/
45	PUBLICATIONS/
46	GOVERNMENT PUBLICATIONS AS TOPIC/
47	PAMPHLETS/
48	INTERNET/
49	HOTLINES/
50	TELEPHONE/
51	patient education handout.pt.

#	Searches
52	(inform\$ or educat\$ or communicat\$ or advi\$ or counsel\$ or support\$).ti,ab.
53	(pamphlet? or leaflet? or booklet? or manual? or brochure? or publication? or handout? or hand out? or poster? or website? or web site? or web page? or webpage? or web based or video? or dvd? or online? or internet? or app? or application? or social media or telephon\$ or phone? or helpline? or help line? or hotline? or hot line?).ti,ab.
54	or/36-53
55	SELF-HELP GROUPS/
56	((support\$ or selfhelp\$ or self help\$) adj3 group?).ti,ab.
57	or/55-56
58	PATIENT CARE PLANNING/
59	CRITICAL PATHWAY/
60	CLINICAL PROTOCOLS/
61	((care adj3 plan\$) or pathway? or protocol?).ti.
62	or/58-61
63	exp "CONTINUITY OF PATIENT CARE"/
64	((patient? or neonat\$ or newborn\$ or new-born\$ or baby or babies or pre#mie? or premie or premies or infant?) adj3 (discharg\$ or handoff? or hand off or handover? or hand\$ over? or transfer\$ or transition\$ or aftercare)).ti,ab.
65	or/63-64
66	INTENSIVE CARE UNITS, PEDIATRIC/
67	INTENSIVE CARE UNITS, NEONATAL/
68	(intensive care adj3 (p?ediatric\$ or neonat\$)).ti,ab.
69	PICU?.ti,ab.
70	NICU?.ti,ab.
71	or/66-70
72	PHYSICIAN-PATIENT RELATIONS/
73	PROFESSIONAL-FAMILY RELATIONS/
74	NURSE-PATIENT RELATIONS/
75	PROFESSIONAL-PATIENT RELATIONS/
76	ATTITUDE OF HEALTH PERSONNEL/
77	((professional? or personnel or doctor? or physician? or general practitioner? or GP? or nurse? or AHP? or pharmacist? or dietician? or neonatologist? or p?ediatrician?) adj5 (famil\$ or parent? or parental or father\$ or mother\$ or grandparent\$ or grandfather\$ or grandmother\$ or carer\$ or caregiver\$) adj5 (relation\$ or interact\$ or involv\$ or meet\$ or collaborat\$ or rapport)).ti,ab.
78	((famil\$ or parent? or parental or father\$ or mother\$ or grandparent\$ or grandfather\$ or grandmother\$ or carer\$ or caregiver\$) adj5 (perception\$ or concern\$ or anxiet\$ or anxious\$)).ti,ab.
79	or/72-78
80	(famil\$ or parent? or parental or father\$ or mother\$ or grandparent\$ or grandfather\$ or grandmother\$ or carer\$ or caregiver\$).ti.
81	(professional? or personnel or doctor? or physician? or general practitioner? or GP? or nurse? or AHP? or pharmacist? or dietician? or neonatologist? or p?ediatrician?).ti.
82	(inform\$ or educat\$ or communicat\$ or advi\$ or counsel\$).ti.
83	or/80-82
84	14 and 26 and (32 or 35) and 54
85	14 and 26 and 57
86	14 and 26 and 62
87	14 and 26 and (32 or 35 or 54) and 65
88	26 and (32 or 35) and 54 and 71
89	14 and 26 and 79
90	14 and 26 and 83
91	or/84-90
92	limit 91 to english language
93	LETTER/
94	EDITORIAL/
95	NEWS/
96	exp HISTORICAL ARTICLE/
97	ANECDOTES AS TOPIC/
98	COMMENT/
99	CASE REPORT/
100	(letter or comment*).ti.
101	or/93-100
102	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
103	101 not 102
104	ANIMALS/ not HUMANS/
105	exp ANIMALS, LABORATORY/
106	exp ANIMAL EXPERIMENTATION/
107	exp MODELS, ANIMAL/
108	exp RODENTIA/

#	Searches
109	(rat or rats or mouse or mice).ti.
110	or/103-109
111	92 not 110

1

2

3

4 Databases: Embase; and Embase Classic

#	Searches
1	NEWBORN/
2	(neonat\$ or newborn\$ or new-born\$ or baby or babies).ti,ab.
3	PREMATURITY/
4	((preterm\$ or pre-term\$ or prematur\$ or pre-matur\$) adj5 (birth? or born)).ab,ti.
5	((preterm\$ or pre-term\$ or prematur\$ or pre-matur\$) adj5 infan\$).ti,ab.
6	(pre#mie? or premie or premies).ti,ab.
7	exp LOW BIRTH WEIGHT/
8	(low adj3 birth adj3 weigh\$ adj5 infan\$).ti,ab.
9	((LBW or VLBW) adj5 infan\$).ti,ab.
10	NEWBORN INTENSIVE CARE/
11	NEONATAL INTENSIVE CARE UNIT/
12	NICU?.ti,ab.
13	or/1-12
14	PARENTERAL NUTRITION/
15	TOTAL PARENTERAL NUTRITION/
16	PERIPHERAL PARENTERAL NUTRITION/
17	PARENTERAL SOLUTIONS/
18	INTRAVENOUS FEEDING/
19	INTRAVENOUS DRUG ADMINISTRATION/ and (nutrition\$ or feed\$ or fed\$).ti,ab.
20	exp INTRAVENOUS CATHETER/ and (nutrition\$ or feed\$ or fed\$).ti,ab.
21	((parenteral\$ or intravenous\$ or intra-venous\$ or IV or venous\$ or infusion?) adj3 (nutrition\$ or feed\$ or fed\$)).ti,ab.
22	((peripheral\$ or central\$) adj3 line? adj3 (nutrition\$ or feed\$ or fed\$)).ti,ab.
23	(catheter\$ adj3 (nutrition\$ or feed\$ or fed\$)).ti,ab.
24	(drip? adj3 (nutrition\$ or feed\$ or fed\$)).ti,ab.
25	or/14-24
26	FAMILY/
27	exp GRANDPARENT/
28	exp PARENT/
29	CAREGIVER/
30	(famil\$ or parent? or parental or father\$ or mother\$ or grandparent\$ or grandfather\$ or grandmother\$ or carer\$ or caregiver\$).ti,ab.
31	or/26-30
32	exp HEALTH CARE PERSONNEL/
33	(professional? or personnel or doctor? or physician? or general practitioner? or GP? or nurse? or AHP? or pharmacist? or dietician? or neonatologist? or p?ediatrician?).ti,ab.
34	or/32-33
35	COUNSELING/
36	DIRECTIVE COUNSELING/
37	exp *EDUCATION/
38	HEALTH EDUCATION/
39	exp *INTERPERSONAL COMMUNICATION/
40	CONSUMER HEALTH INFORMATION/
41	PATIENT EDUCATION/
42	INFORMATION SEEKING/
43	PUBLICATION/
44	INTERNET/
45	HOTLINE/
46	TELEPHONE/
47	(inform\$ or educat\$ or communicat\$ or advi\$ or counsel\$ or support\$).ti,ab.
48	(pamphlet? or leaflet? or booklet? or manual? or brochure? or publication? or handout? or hand out? or poster? or website? or web site? or web page? or webpage? or web based or video? or dvd? or online? or internet? or app? or application? or social media or telephon\$ or phone? or helpline? or help line? or hotline? or hot line?).ti,ab.
49	or/35-48

#	Searches
50	SELF HELP/
51	((support\$ or selfhelp\$ or self help\$) adj3 group?).ti,ab.
52	or/50-51
53	PATIENT CARE PLANNING/
54	CLINICAL PATHWAY/
55	CLINICAL PROTOCOL/
56	((care adj3 plan\$) or pathway? or protocol?).ti.
57	or/53-56
58	PATIENT CARE/
59	exp CLINICAL HANDOVER/
60	((patient? or neonat\$ or newborn\$ or new-born\$ or baby or babies or pre#mie? or premie or premies or infant?) adj3 (discharg\$ or handoff? or hand off or handover? or hand\$ over? or transfer\$ or transition\$ or aftercare)).ti,ab.
61	or/58-60
62	PEDIATRIC INTENSIVE CARE UNIT/
63	NEONATAL INTENSIVE CARE UNIT/
64	(intensive care adj3 (p?ediatric\$ or neonat\$)).ti,ab.
65	PICU?.ti,ab.
66	NICU?.ti,ab.
67	or/62-66
68	DOCTOR PATIENT RELATION/
69	NURSE PATIENT RELATIONSHIP/
70	PROFESSIONAL PATIENT RELATIONSHIP/
71	HEALTH PERSONNEL ATTITUDE/
72	((professional? or personnel or doctor? or physician? or general practitioner? or GP? or nurse? or AHP? or pharmacist? or dietician? or neonatologist? or p?ediatrician?) adj5 (famil\$ or parent? or parental or father\$ or mother\$ or grandparent\$ or grandfather\$ or grandmother\$ or carer\$ or caregiver\$) adj5 (relation\$ or interact\$ or involv\$ or meet\$ or collaborat\$ or rapport)).ti,ab.
73	((famil\$ or parent? or parental or father\$ or mother\$ or grandparent\$ or grandfather\$ or grandmother\$ or carer\$ or caregiver\$) adj5 (perception\$ or concern\$ or anxiet\$ or anxious\$)).ti,ab.
74	or/68-73
75	(famil\$ or parent? or parental or father\$ or mother\$ or grandparent\$ or grandfather\$ or grandmother\$ or carer\$ or caregiver\$).ti.
76	(professional? or personnel or doctor? or physician? or general practitioner? or GP? or nurse? or AHP? or pharmacist? or dietician? or neonatologist? or p?ediatrician?).ti.
77	(inform\$ or educat\$ or communicat\$ or advi\$ or counsel\$).ti.
78	or/75-77
79	13 and 25 and (31 or 34) and 49
80	13 and 25 and 52
81	13 and 25 and 57
82	13 and 25 and (31 or 34 or 49) and 61
83	25 and (31 or 34) and 49 and 67
84	13 and 25 and 74
85	13 and 25 and 78
86	or/79-85
87	limit 86 to english language
88	letter.pt. or LETTER/
89	note.pt.
90	editorial.pt.
91	CASE REPORT/ or CASE STUDY/
92	(letter or comment*).ti.
93	or/88-92
94	RANDOMIZED CONTROLLED TRIAL/ or random*.ti,ab.
95	93 not 94
96	ANIMAL/ not HUMAN/
97	NONHUMAN/
98	exp ANIMAL EXPERIMENT/
99	exp EXPERIMENTAL ANIMAL/
100	ANIMAL MODEL/
101	exp RODENT/
102	(rat or rats or mouse or mice).ti.
103	or/95-102
104	87 not 103

1 **Databases: Cochrane Central Register of Controlled Trials; Cochrane Database of**
2 **Systematic Reviews; Database of Abstracts of Reviews of Effects; and Health**
3 **Technology Assessment**

#	Searches
1	MeSH descriptor: [Infant, Newborn] this term only
2	(neonat* or newborn* or new-born* or baby or babies):ti,ab
3	MeSH descriptor: [Premature Birth] this term only
4	((preterm* or pre-term* or prematur* or pre-matur*) near/5 (birth* or born)):ti,ab
5	MeSH descriptor: [Infant, Premature] explode all trees
6	((preterm* or pre-term* or prematur* or pre-matur*) near/5 infan*):ti,ab
7	(pre?mie? or premie or premies):ti,ab
8	MeSH descriptor: [Infant, Low Birth Weight] explode all trees
9	(low near/3 birth near/3 weigh* near/5 infan*):ti,ab
10	((LBW or VLBW) near/5 infan*):ti,ab
11	MeSH descriptor: [Intensive Care, Neonatal] this term only
12	MeSH descriptor: [Intensive Care Units, Neonatal] this term only
13	NICU?:ti,ab
14	#1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13
15	MeSH descriptor: [Parenteral Nutrition] this term only
16	MeSH descriptor: [Parenteral Nutrition, Total] this term only
17	MeSH descriptor: [Parenteral Nutrition Solutions] this term only
18	MeSH descriptor: [Administration, Intravenous] this term only
19	MeSH descriptor: [Infusions, Intravenous] this term only
20	MeSH descriptor: [Catheterization, Central Venous] this term only
21	MeSH descriptor: [Catheterization, Peripheral] explode all trees
22	#18 or #19 or #20 or #21
23	(nutrition* or feed* or fed*) .ti,ab.
24	#22 and #23
25	((parenteral* or intravenous* or intra-venous* or IV or venous* or infusion?) near/3 (nutrition* or feed* or fed*) .ti,ab.
26	((peripheral* or central*) near/3 line? near/3 (nutrition* or feed* or fed*)) .ti,ab.
27	(catheter* near/3 (nutrition* or feed* or fed*)) .ti,ab.
28	(drip? near/3 (nutrition* or feed* or fed*)) .ti,ab.
29	#15 or #16 or #17 or #24 or #25 or #26 or #27 or #28
30	MeSH descriptor: [Family] this term only
31	MeSH descriptor: [Grandparents] this term only
32	MeSH descriptor: [Parents] explode all trees
33	MeSH descriptor: [Caregivers] this term only
34	(famil* or parent* or parental or father* or mother* or grandparent* or grandfather* or grandmother* or carer* or caregiver*):ti,ab
35	#30 or #31 or #32 or #33 or #34
36	MeSH descriptor: [Health Personnel] explode all trees
37	(professional* or personnel or doctor* or physician* or "general practitioner*" or GP* or nurse* or AHP* or pharmacist* or dietician* or neonatologist* or pediatrician* or paediatrician*):ti,ab
38	#36 or #37
39	MeSH descriptor: [Counseling] this term only
40	MeSH descriptor: [Directive Counseling] this term only
41	MeSH descriptor: [Education] explode all trees
42	MeSH descriptor: [Health Education] this term only
43	MeSH descriptor: [Communication] explode all trees
44	MeSH descriptor: [Consumer Health Information] explode all trees
45	MeSH descriptor: [Patient Education as Topic] this term only
46	MeSH descriptor: [Information Seeking Behavior] this term only
47	MeSH descriptor: [Posters as Topic] this term only
48	MeSH descriptor: [Publications] this term only
49	MeSH descriptor: [Government Publications as Topic] this term only
50	MeSH descriptor: [Pamphlets] this term only
51	MeSH descriptor: [Internet] this term only
52	MeSH descriptor: [Hotlines] this term only
53	MeSH descriptor: [Telephone] this term only
54	(inform* or educat* or communicat* or advi* or counsel* or support*):ti,ab
55	(pamphlet* or leaflet* or booklet* or manual* or brochure* or publication* or handout* or "hand out*" or poster* or website* or "web site*" or "web page*" or webpage* or "web based" or video* or dvd* or online* or internet* or app* or application* or "social media" or telephon* or phone* or helpline* or "help line*" or hotline* or "hot line*"):ti,ab
56	#39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or #49 or #50 or #51 or #52 or #53 or #54 or #55
57	MeSH descriptor: [Self-Help Groups] this term only
58	((support* or selfhelp* or "self help*") near/3 group*):ti,ab

#	Searches
59	#57 or #58
60	MeSH descriptor: [Patient Care Planning] this term only
61	MeSH descriptor: [Critical Pathways] this term only
62	MeSH descriptor: [Clinical Protocols] this term only
63	((care near/3 plan*) or pathway* or protocol*):ti
64	#60 or #61 or #62 or #63
65	MeSH descriptor: [Continuity of Patient Care] explode all trees
66	((patient* or neonat* or newborn* or "new-born*" or baby or babies or premie or premies or infant*) near/3 (discharg* or handoff* or "hand off" or handover* or "hand* over*" or transfer* or transition* or aftercare)):ti,ab
67	#65 or #66
68	MeSH descriptor: [Intensive Care Units, Pediatric] this term only
69	MeSH descriptor: [Intensive Care Units, Neonatal] this term only
70	("intensive care" near/3 (pediatric* or paediatric* or neonat*)):ti,ab
71	PICU*:ti,ab
72	NICU*:ti,ab
73	#68 or #69 or #70 or #71 or #72
74	MeSH descriptor: [Physician-Patient Relations] this term only
75	MeSH descriptor: [Professional-Family Relations] this term only
76	MeSH descriptor: [Nurse-Patient Relations] this term only
77	MeSH descriptor: [Professional-Patient Relations] this term only
78	MeSH descriptor: [Attitude of Health Personnel] this term only
79	((professional* or personnel or doctor* or physician* or "general practitioner*" or GP* or nurse* or AHP* or pharmacist* or dietician* or neonatologist* or pediatrician* or paediatrician*) near/5 (famil* or parent* or parental or father* or mother* or grandparent* or grandfather* or grandmother* or carer* or caregiver*) near/5 (relation* or interact* or involv* or meet* or collaborat* or rapport)):ti,ab
80	((famil* or parent* or parental or father* or mother* or grandparent* or grandfather* or grandmother* or carer* or caregiver*) near/5 (perception* or concern* or anxiet* or anxious*)):ti,ab
81	#74 or #75 or #76 or #77 or #78 or #79 or #80
82	(famil* or parent* or parental or father* or mother* or grandparent* or grandfather* or grandmother* or carer* or caregiver*) .ti
83	(professional* or personnel or doctor* or physician* or "general practitioner*" or GP* or nurse* or AHP* or pharmacist* or dietician* or neonatologist* or pediatrician* or paediatrician*) .ti
84	(inform* or educat* or communicat* or advi* or counsel*) .ti
85	#82 or #83 or #84
86	#14 and #29 and (#35 or #38) and #56
87	#14 and #29 and #59
88	#14 and #29 and #64
89	#14 and #29 and (#35 or #38 or #56) and #67
90	#29 and (#35 or #38) and #56 and #73
91	#14 and #29 and #81
92	#14 and #29 and #85
93	#86 or #87 or #88 or #89 or #90 or #91 or #92

1

2 Databases: Web of Science – Conference Proceedings Citation Index- Science

3

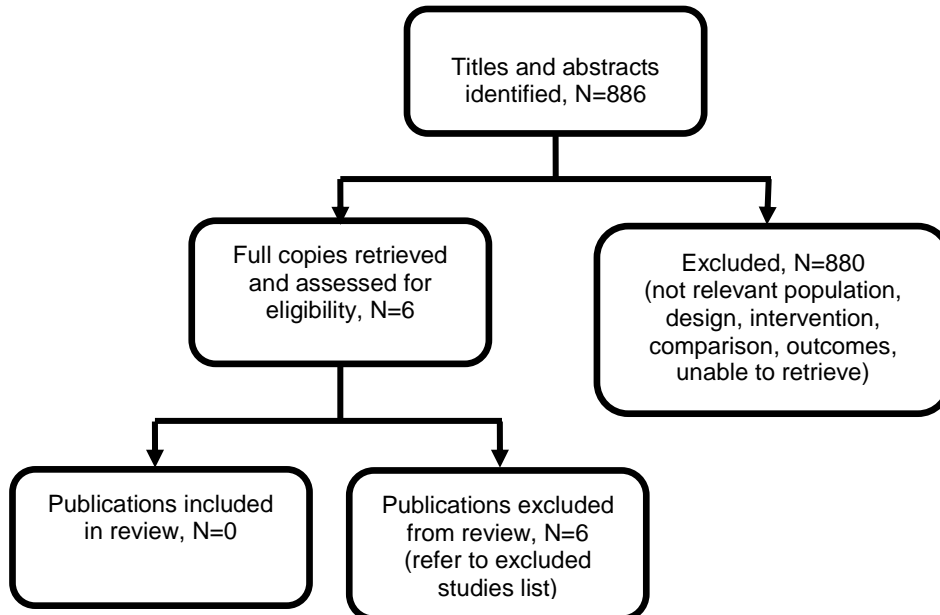
#	Searches
1	TOPIC: (neonat* or newborn* or new-born* or baby or babies or premie\$ or infant\$)
2	TOPIC: ((parenteral* or intravenous* or intra-venous* or venous* or infusion\$) near/3 (nutrition* or feed* or fed*))
3	TOPIC: (inform* or educat* or communicat* or advi* or counsel*)
4	TOPIC: (pamphlet\$ or leaflet\$ or booklet\$ or manual\$ or brochure\$ or publication\$ or handout\$ or hand out\$ or poster\$ or website\$ or web site\$ or web page\$ or webpage\$ or web based or video\$ or dvd\$ or online\$ or internet\$ or app\$ or application\$ or social media or telephon* or phone\$ or helpline\$ or help line\$ or hotline\$ or hot line\$)
5	#4 OR #3
6	#5 AND #2 AND #1

4

1 Appendix C – Clinical evidence study selection

2 **Clinical evidence study selection for review question: What are the most effective**
3 **methods of information provision about PN and what information and support**
4 **do parents or carers perceive as useful?**

5



6

1 **Appendix D – Clinical evidence tables**

2 **Clinical evidence tables for review question: What are the most effective methods of**
3 **information provision about PN and what information and support do parents or**
4 **carers perceive as useful?**

5 No studies were identified which were applicable to this review question.

6

1 **Appendix E – Forest plots**

- 2 **Clinical evidence forest plots for review question: What are the most effective**
- 3 **methods of information provision about PN and what information and support**
- 4 **do parents or carers perceive as useful?**
- 5 No studies were identified which were applicable to this review question.

1 **Appendix F – GRADE tables**

2

3 **Clinical evidence GRADE tables for review question: What are the most effective**
4 **methods of information provision about PN and what information and support**
5 **do parents or carers perceive as useful?**

6 No studies were identified which were applicable to this review question.

1 **Appendix G – Economic evidence study selection**

2 **Economic evidence study selection for review question: What are the most** 3 **effective methods of information provision about PN and what information and** 4 **support do parents or carers perceive as useful?**

5 One global search was conducted for all review questions. See supplementary material D for
6 further information.

1 **Appendix H – Economic evidence tables**

2 **Economic evidence tables for review question: What are the most effective**
3 **methods of information provision about PN and what information and support**
4 **do parents or carers perceive as useful?**

5 No economic studies were identified which were applicable to this review question.

6

1 **Appendix I – Economic evidence profiles**

2 **Economic evidence profiles for review question: What are the most effective**
3 **methods of information provision about PN and what information and support**
4 **do parents or carers perceive as useful?**

5 No economic studies were identified which were applicable to this review question.

1 **Appendix J – Economic analysis**

2 **Economic analysis for review question: What are the most effective methods of**
3 **information provision about PN and what information and support do parents**
4 **or carers perceive as useful?**

5 No economic analysis was undertaken for this review question.

1 Appendix K – Excluded studies

2 Excluded studies for review question: What are the most effective methods of 3 information provision about PN and what information and support do parents 4 or carers perceive as useful?

5 Clinical studies

6 Table 3: Excluded studies and reasons for their exclusion

Study	Reason for Exclusion
Ahmed, Mansoor, Irwin, Sarah, Tuthill, David P., Education and evidence are needed to improve neonatal parenteral nutrition practice, JPEN. Journal of parenteral and enteral nutrition, 28, 176-9, 2004	Study intervention does not meet protocol eligibility criteria - survey on PN nutrients and composition; Does not assess information/support to parents/carers.
Akkoyun, Sevinc, Tas Arslan, Fatma, Investigation of stress and nursing support in mothers of preterm infants in neonatal intensive care units, Scandinavian journal of caring sciences, 2018	Study design does not meet inclusion criteria; quantitative study of how much stress was experienced by mothers and how much support they received from nurses.
Al-Rafay, Safy S., Al-Sharkawy, Sabah S., Educational outcomes associated with providing a comprehensive guidelines program about nursing care of preterm neonates receiving total parenteral nutrition, Clinical nursing research, 21, 142-58, 2012	Study intervention does not meet protocol eligibility criteria - educational programme for nurses; Does not assess information/support to parents/carers.
Bailey, Sean M., Hendricks-Munoz, Karen D., Mally, Pradeep, Parental influence on clinical management during neonatal intensive care: a survey of US neonatologists, The journal of maternal-fetal & neonatal medicine : the official journal of the European Association of Perinatal Medicine, the Federation of Asia and Oceania Perinatal Societies, the International Society of Perinatal Obstetricians, 26, 1239-44, 2013	Study intervention does not meet protocol eligibility criteria - does not assess information/support for parents/carers of neonates on PN.
Fisher, A. A., Poole, R. L., Machie, R., Tsang, C., Baugh, N., Utley, K., Kerner, J. A., Jr., Clinical pathway for pediatric parenteral nutrition, Nutrition in clinical practice : official publication of the American Society for Parenteral and Enteral Nutrition, 12, 76-80, 1997	Study intervention does not meet protocol eligibility criteria - clinical pathway does not include information/support for parents/carers.
Raiskila, S., Axelin, A., Rapeli, S., Vasko, I., Lehtonen, L., Trends in care practices reflecting parental involvement in neonatal care, Early Human Development, 90, 863-867, 2014	Study intervention does not meet eligibility criteria; family centred care with nutritional focus on enteral and breastfeeding, does not describe information/support provided to parents/carers.

7 Economic studies

8 No economic evidence was identified for this review question. See supplementary material D
9 for further information.

1 Appendix L – Research recommendations

2 Research recommendation for review question: What are the most effective 3 methods of information provision about PN and what information and support 4 do parents or carers perceive as useful?

5 Research recommendation

6 What are the information and support needs of parents with babies on parenteral nutrition?

7 Why this is important

8 Having a baby in a neonatal unit can be a stressful and difficult time for parents and carers.
9 Information and support can help parents manage these circumstances and help them feel
10 involved and part of the care of their baby which can improve outcomes. Currently there is no
11 evidence about what information and support parents might need in relation to PN. There are
12 also very few sources of information available. Given that the number of babies needing PN
13 is likely to increase as prematurity survival rates improve, understanding what information
14 and support parents best need will help meet the demands of this population and help
15 support good outcomes.

16 **Table 4: Research recommendation rationale**

Research question	What are the information and support needs of parents with babies on parenteral nutrition?
Why is this needed	
Importance to 'patients' or the population	High: The right information and support (including psychological support) can make having a child in a neonatal unit less stressful and increase the ability of parents and carers to bond with and care for their child. Parenteral nutrition is an essential part of babies care and replaces (or partly replaces) the parents' role in feeding their baby so ensuring parents understand it is an essential part of good care.
Relevance to NICE guidance	High: The review found no evidence on the information and support needs of parents and carers.
Relevance to the NHS	High: Improving the information and support to parents and carers will improve their experience of services and help them be involved in the care of their baby and achieve good outcomes
National priorities	The NHS Long term plan (launched in January 2019) for the next 10 years highlights 'enabling everyone to get the best start in life' as one of the main areas to improve the quality of patient care and health outcomes. Improving the experiences of parents of preterm babies which would also impact on the baby would fall into this priority bracket.
Current evidence base	The guideline identified that there is a gap in the evidence base. The systematic review of this

Research question	What are the information and support needs of parents with babies on parenteral nutrition?
	topic did not find any comparative effectiveness or qualitative evidence addressing this topic. Currently information on this is anecdotal.
Equality	Younger and older mothers are more likely to have premature babies and may have different information requirements from each other. There may be socioeconomic differences between parents and carers information and support needs. Some parents and cares may need information in different languages and there may be cultural sensitivities around PN. Those with learning disabilities may need additional formats or support.
Feasibility	This would involve observations or interviews and would therefore be feasible to do.
Other comments	The NICE guideline committee identified this as an area where little information is available that directly addresses the needs that they have. Therefore such research would be beneficial in bridging this gap.

1 NHS: National Health Service; NICE: National Institute for Health and Care Excellence; PN: Parenteral nutrition

2 **Table 5: Research recommendation modified PICO table**

Criterion	Explanation
Population	<ul style="list-style-type: none"> Parents and carers of babies receiving PN in a neonatal unit Healthcare professionals supporting those parents and carers whose babies are on PN
Interest	Experience of information and support that is provided (or is lacking) to parents or carers of babies receiving neonatal parenteral nutrition.
Context	UK NHS neonatal units
Study design	<p>Qualitative study design using either a 'grounded theory' or 'phenomenological' approach.</p> <p>This may involve conducting interviews or direct observations or a mixture of both.</p>
Timeframe	<ul style="list-style-type: none"> Parenteral or healthcare professionals' experience throughout the time of PN provision (from a baby starting PN until PN is discontinued); this may include one or several interviews or observations at different times during the hospital admission of the baby Overall data collection and analysis would be 2 years
Additional information	None.

3 PN: Parenteral nutrition