

Appendices

A. Survey



- **Service user and health professional organisations are working together to gather the most important ideas for research about preterm birth and caring for premature babies. This is called the 'James Lind Alliance (JLA) Preterm Birth Priority Setting Partnership (PSP)'.**
- **All the research questions that need answering will be published in UK Database of Uncertainties about the Effects of Treatments (www.library.nhs.uk/duets).**
- **For more information about this project, please visit [here](#)**
- **This survey is also available on-line. Go to <http://www.surveymonkey.com/s/prembabies> to take part in this way.**

PART ONE – YOUR SUGGESTIONS OR QUESTIONS FOR RESEARCH ABOUT PRETERM BIRTH AND PREMATURE BABIES

You are invited to suggest topics or questions about preterm birth and caring for premature babies. You can make suggestions about the followings or anything else:

- How to investigate the causes of preterm birth?
- Are there better ways of preventing or treating preterm birth or caring for premature babies?
- Whether treatments are safe or effective?
- Family care and support?

Examples for other health conditions:

- *Does listening to babies' hearts when they are three months old find those babies that need special heart care?*
- *Do 'buddies' (or peer support) benefit children with Down's syndrome and their families?*

QUESTION 1 YOUR SUGGESTION OR QUESTION

Is there an experience, service or treatment about preterm birth which needs to be researched? (If you have more than one suggestions, we would like to hear all of them. You can add them later.)

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QUESTION 2 [OPTIONAL]

How, or why is your suggestion or question important to you, other people, or for particular reasons?

QUESTION 3 More questions

Do you have another suggestion or question?

QUESTION 4 YOUR SUGGESTION OR QUESTION

Is there an experience, service or treatment about preterm birth which need to be researched? (If you have more suggestions, we would like to hear all of them. You can add them later.)

QUESTION 5 [OPTIONAL]

How, or why is your suggestion or question important to you, other people, or for particular reasons?

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QUESTION 6 More questions

Do you have other suggestion or question?

QUESTION 7 YOUR SUGGESTION OR QUESTION

Is there an experience, service or treatment about preterm birth which need to be researched? (If you have more suggestions, we would like to hear all of them. You can add them later.)

QUESTION 8 [OPTIONAL]

How, or why is your suggestion or question important to you, other people, or for particular reasons?

QUESTION 9 More questions

Do you have other suggestions or questions?

QUESTION 10 YOUR SUGGESTION OR QUESTION

Is there an experience, service or treatment about preterm birth which need to be researched? (If you have more suggestions, we would like to hear all of them. You can add them later.)

QUESTION 11 [OPTIONAL]

How, or why is your suggestion or question important to you, other people, or for particular reasons?

QUESTION 12 More questions

Do you have other suggestion or question?

QUESTION 13 YOUR SUGGESTION OR QUESTION

Is there an experience, service or treatment about preterm birth which need to be researched? (If you have more suggestions, we would like to hear all of them. You can add them later.)

QUESTION 14 [OPTIONAL]

How or why is your suggestion or question important to you, other people, or for particular reasons?

PART TWO – ABOUT YOU (The following information is helpful us to understand backgrounds of people, who have answered this survey. The information will be collected anonymously for statistical purpose. If you wish you can skip the questions.)

QUESTION 15 Are you_____?

(Please tick the appropriate option)

- Service user (parent, family, grandparent, carer etc) – Go to Question 16
- health care professional– Go to Question 20
- Both service user and health care professional – Go to Question 16

QUESTION 16 (Service users only) Are you_____?

- Parent of (a) preterm babies
- Someone who was born prematurely
- Grandparent of (a) preterm babies
- Carer of (a) preterm babies or families with (a) preterm babies
- Other family member of (a) preterm babies
- Other - Please specify_____
- Prefer not to say

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QUESTION 17 Are you _____?

(Please tick the appropriate option)

- Female
- Male

QUESTION 18 How would you describe your ethnic group?

(Please tick the appropriate option)

- White
- Mixed
- Asian
- Black
- Chinese
- Other Ethnic Group

QUESTION 19

What are your highest educational qualifications?

(If you have educated in non-British educational system, please select the closest British equivalent to your highest qualification.)

- None
- NVQ or BTEC
- GCSE
- A Level
- University degree
- Postgraduate degree
- Prefer not to say

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**QUESTION 20 Can you please describe the housing that you are currently living in?
(Please select the closest one)**

- own property (or have mortgage)
- rented accommodation
- living with family or relatives
- Other accommodation (please specify) _____
- Prefer not to say

QUESTION 21 (Health Care Professionals only)

Please tell us what kind of health care professional you are.

- Midwife
- Nurse (Please state specialism, eg Neonatal nurse) _____
- General practitioner
- Obstetrician(Please state seniority, eg Consultant, Registrar or SHO) _____
- Neonatologist (Please state seniority, eg Consultant, Registrar or SHO) _____
- Other Medical doctor or surgeon (Please state specialism) _____
- Other - Please specify _____
- Prefer not to say

QUESTION 22

Can you please describe the housing that you are currently living in?

(Please select the closest one)

- own property (or have mortgage)
- rented accommodation
- living with family or relatives
- Other accommodation

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PART 3 You have completed the survey - thank you for taking part.

The next stage is to prioritise the unanswered questions for research. We will keep you informed via our website (<http://eppi.ioe.ac.uk/pretermbirth>) and Twitter feed (@PretermBirth).

To get involved, or to find out more, please fill in your contact details below (these will be stored securely and not passed on to anyone else).

Title_____
First Name _____
Family Name_____
Address_____

To order a pre-paid envelope please contact Seilin (s.uhm@ioe.ac.uk): Social Science Research Unit, Institute of Education, University of London, 18 Woburn Square, London WC1H 0NR, Tel: +44(0)20 7612 6532 (Direct)

*This survey is also available on-line. Go to <http://www.surveymonkey.com/s/prembabies> to take part in this way. **Thank you for your participation!***

B. Top thirty priorities, and degree of support, before discussion at the Final Workshop

	HC A	Service users	Both	Total n=537, %	
Which treatments (including diagnostic tests) are most effective to predict or prevent preterm birth?	106	84	36	226	42%
What is the optimum milk feeding regimen, for preterm infants, including quantity and speed of feeding and use of donor and formula milks.	87	69	26	182	34%
How do stress, trauma and physical workload contribute to the risk of preterm birth, are there effective ways to reduce those risks and does modifying those risks alter outcome?	29	72	24	125	23%
What treatments can predict reliably the likelihood of subsequent infants being preterm?	30	74	18	122	23%
Which treatments are most effective to prevent pre-eclampsia (for example, progesterone, calcium, garlic etc)?	41	61	16	118	22%
What should be included in packages of care to support parents and families / carers when a premature baby is discharged from hospital?	19	71	21	111	21%
Is screening in the first trimester effective to help prevent preterm birth?	38	43	18	99	18%
How can infection in preterm infants be better prevented?	32	51	14	97	18%
Which treatments are most effective to prevent necrotising enterocolitis in preterm infants?	45	33	10	88	16%

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Which treatments are effective in preventing spontaneous preterm birth in women with twin and triplet pregnancies, especially in those at high risk of preterm birth?	41	34	10	85	16%
Does specialist prenatal care, for women showing signs of preterm birth, improve morbidity and mortality in mother and baby?	34	36	12	82	15%
What type of support is most effective at improving breastfeeding in NICU/SCBU/feeding clinics?	24	37	19	80	15%
Can screening of the placenta be effective to detect placenta abnormalities associated with preterm birth?	19	51	10	80	15%
What is the best way to judge whether a baby is feeling pain (for example, by their face, behaviours, or brain activities)?	20	45	12	77	14%
Does screening and treatment for Group B Streptococcus help to prevent preterm birth and neonatal morbidity and mortality?	38	30	8	76	14%
Which treatments are most effective for premature rupture of membranes?	26	42	7	75	14%
What methods are most effective to predict risk of preterm birth in order to allocate service provision?	41	24	8	73	14%
Is routine transvaginal scanning during pregnancy to detect short cervical length, and treatment, cost effective?	41	22	7	70	13%
What is the best time to clamp the umbilical cord for preterm babies?	36	29	5	70	13%

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What is the best treatment for life-threatening lung damage in preterm infants?	25	31	10	66	12%
What guidance and information is most useful for parents at risk of having preterm infants?	27	31	5	63	12%
Which treatments are most effective for necrotising enterocolitis in preterm infants?	31	26	6	63	12%
What is the best way to encourage Kangaroo Mother Care more by staff in NICU for parents?	18	33	11	62	12%
What is the impact of length of orogastric / nasogastric feeding and reflux on early feeding development in preterm infants?	22	31	9	62	12%
Which treatments improve attachment and bonding and does the promotion of appropriate attachment and bonding improve outcomes?	11	38	11	60	12%
What are the best ways to optimise the environment in order to improve outcomes (for example cycled light, eye masks, ear muffs or music therapy)?	16	30	13	59	11%
Do parents of preterm infants benefit from an open approach to notes and ward rounds?	14	32	12	58	11%
What emotional and practical support should be included in a care bundle that aims to optimise outcomes of preterm birth?	15	32	9	56	10%
Do preterm babies have better outcomes if their parents have roomed in?	9	29	15	53	10%
Which lifestyle changes including gym, bed rest, posture and sexual intercourse	12	32	8	52	10%

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are effective to minimise the risk of preterm birth?					
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c. Sampling framework for participants in the Preterm Birth

Workshop Tuesday 14th January 2014

(Names were written in initials)

Service Users: (Bliss, NCT, Tiny Lives, Survey responders)	Name	Geographical	Ethnicity	Recent experience?	Place of care/ Moved care?	Pathway to pre term: spontaneous or induced?	Multiple birth?
Preterm - adult x 2	PJ (SG)	London	White	N/A			
Dads x 2							
Wider family members (e.g. siblings and grandparents) x 2							
Under 24 weeks x 2	AS		BME	1995	London	Spontaneous	
24 – 28 weeks x 2							
29 – 32 weeks x 2							
33+ weeks x 2							
Still birth x 2	BC (SG)	South Coast	White	Mother to 21 yr old pre term baby			

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Sub total = 16							
Health Professionals:							
(RCOG, RCN professional organisations affiliated, survey responders)							
3 x Midwives	JM (SG)	Rep of Ireland					
3 x Neonatologists	MT (SG)	Liverpool	White				
	CG (SG)	London	White				
4x Obstetricians	PJ (a/a)						
	AD (SG)	London	White				
	AS (SG/RCOG)						
	JD(BJOG)	London	Asian				
3 x Neonatology nurses (inc 1 x specialist practitioner)							
1 x GP							
1 x Paediatric Anaesthetist	SW	London	White				
1 x Health Visitor							
1 x Physiotherapist							
1 x Speech therapist							
1 x Social Worker							
1 x Psychologist/counsellor							

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1 x Paediatric Surgeon (TBC)							
1 x advice line family support	CB						
Sub tot = 22							
Support roles:							
	GG (NCT) ZC (Bliss) CL(Prog Grant)						
	IK	Manchester	Other (Korean)				
Facilitators							
	SC (JLA) SO (IOE) FA (Cochrane and Tiny Lives)						
Observers	Lelia Duley Prog Grant and CTU Funde						
	Seilin Uhm						
Grand Total = 32							

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D. Priorities from small groups at the Final Workshop

Morning session					
Uncertainty	Grp 1	Grp 2	Grp 3	Grp 4	Total
Which treatments (including diagnostic tests) are most effective to predict or prevent preterm birth?	1	1	1	1	4
How can infection in preterm infants be better prevented?	5	3	3	7	18
Which interventions are most effective to <u>prevent</u> necrotising enterocolitis in preterm infants?	4	4	2	8	18
What is the best treatment for life-threatening lung damage in preterm infants?	11	5	9	4	29
What should be included in packages of care to support parents and families / carers when a premature baby is discharged from hospital?	12	8	7	5	32
What is the best way to judge whether a baby is feeling pain (for example, by their face, behaviours or brain activities)?	14	7	10	2	33
What is the optimum milk feeding regimen, for preterm infants, including quantity and speed of feeding and use of donor and formula milks?	8	2	15	13	38
Which treatments are most effective to prevent pre-eclampsia (for example, progesterone, calcium, garlic etc)?	3	26	4	6	39
Which treatments improve attachment and bonding and does the promotion of appropriate attachment and bonding improve outcomes?	2	10	21	11	44

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Which treatments are most effective for premature rupture of membranes?	13	15	5	14	47
What emotional and practical support should be included in a care bundle that aims to optimise outcomes of preterm birth?	23	6	19	3	51
What is the best time to clamp the umbilical cord for preterm babies?	19	12	17	9	57
Which treatments are most effective <u>to treat</u> necrotising enterocolitis in preterm infants?	20	11	14	17	62
What type of support is most effective at improving breastfeeding in NICU/SCBU/feeding clinics?	7	13	23	19	62
Does specialist prenatal care, for women showing signs of preterm birth, improve morbidity and mortality in mother and baby?	16	22	13	12	63
Is screening in the first trimester effective to help prevent preterm birth?	6	23	20	15	64
What are the best ways to optimise the environment in order to improve outcomes (for example cycled light, eye masks, ear muffs or music therapy)?	27	20	11	10	68
Which treatments are effective in preventing spontaneous preterm birth in women with twin and triplet pregnancies, especially in those at high risk of preterm birth?	10	19	12	29	70
What guidance and information is most useful for parents at risk of having preterm infants?	17	21	18	16	72
Is routine transvaginal scanning during pregnancy to detect short cervical length, and treatment, cost effective?	15	14	24	20	73

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Does screening and treatment for Group B Streptococcus help to prevent preterm birth and neonatal morbidity and mortality?	9	17	28	21	75
How do stress, trauma and physical workload contribute to the risk of preterm birth, are there effective ways to reduce those risks and does modifying those risks alter outcome?	22	29	6	25	82
What is the impact of length of orogastric / nasogastric feeding and reflux on early feeding development in preterm infants?	25	9	26	23	83
What methods are most effective to predict risk of preterm birth in order to allocate service provision?	26	18	22	18	84
Can screening of the placenta be effective to detect placenta abnormalities associated with preterm birth?	28	27	8	22	85
What is the best way to encourage Kangaroo Mother Care more by staff in NICU for parents?	24	16	25	24	89
What treatments can predict reliably the likelihood of subsequent infants being preterm?	21	24	16	30	91
Do parents of preterm infants benefit from an open approach to notes and ward rounds?	18	30	29	26	103
Do preterm babies have better outcomes if their parents have roomed in?	30	25	30	27	112
Which lifestyle changes including gym, bed rest, posture and sexual intercourse are effective to minimise the risk of preterm birth?	29	28	27	28	112
Afternoon session					
Uncertainty	Grp A		Grp B	Grp C	Total

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Which treatments (including diagnostic tests) are most effective to predict or prevent preterm birth?	1	1	1	3
How can infection in preterm infants be better prevented?	2	2	2	6
Which interventions are most effective to <u>prevent</u> necrotising enterocolitis in preterm infants?	3	3	3	9
What is the best treatment for life-threatening lung damage in preterm infants?	4	4	4	12
What should be included in packages of care to support parents and families / carers when a premature baby is discharged from hospital?	5	5	6	16
What is the optimum milk feeding regimen, for preterm infants, including quantity and speed of feeding and use of donor and formula milks?	6	6	8	20
What is the best way to judge whether a baby is feeling pain (for example, by their face, behaviours or brain activities)?	8	7	7	22
Which treatments are most effective to prevent pre-eclampsia (for example, progesterone, calcium, garlic etc)?	7	12	5	24
Which treatments improve attachment and bonding and does the promotion of appropriate attachment and bonding improve outcomes?	9	14	9	32
What emotional and practical support should be included in a care bundle that aims to optimise outcomes of preterm birth?	13	8	11	32
Which treatments are most effective for premature rupture of membranes?	10	13	10	33

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What is the best time to clamp the umbilical cord for preterm babies?	14	11	12	37
What type of support is most effective at improving breastfeeding in NICU/SCBU/feeding clinics?	16	10	14	40
Which treatments are most effective <u>to treat</u> necrotising enterocolitis in preterm infants?	15	15	13	43
Does specialist prenatal care, for women showing signs of preterm birth, improve morbidity and mortality in mother and baby?	12	16	15	43
What are the best ways to optimise the environment in order to improve outcomes (for example cycled light, eye masks, ear muffs or music therapy)?	18	9	18	45
Is screening in the first trimester effective to help prevent preterm birth?	17	17	19	53
Which treatments are effective in preventing spontaneous preterm birth in women with twin and triplet pregnancies, especially in those at high risk of preterm birth?	19	19	16	54
How do stress, trauma and physical workload contribute to the risk of preterm birth, are there effective ways to reduce those risks and does modifying those risks alter outcome?	11	22	22	55
Is routine transvaginal scanning during pregnancy to detect short cervical length, and treatment, cost effective?	21	18	17	56
What guidance and information is most useful for parents at risk of having preterm infants?	20	20	20	60
Does screening and treatment for Group B Streptococcus help to prevent preterm birth and neonatal morbidity and mortality?	22	21	21	64

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What is the impact of length of orogastric / nasogastric feeding and reflux on early feeding development in preterm infants?	23	23	23	69
What methods are most effective to predict risk of preterm birth in order to allocate service provision?	24	24	24	72
Can screening of the placenta be effective to detect placenta abnormalities associated with preterm birth?	25	25	25	75
What is the best way to encourage Kangaroo Mother Care more by staff in NICU for parents?	26	26	26	78
What treatments can predict reliably the likelihood of subsequent infants being preterm?	27	27	27	81
Do parents of preterm infants benefit from an open approach to notes and ward rounds?	28	28	28	84
Do preterm babies have better outcomes if their parents have roomed in?	29	29	29	87
Which lifestyle changes including gym, bed rest, posture and sexual intercourse are effective to minimise the risk of preterm birth?	30	30	30	90
What is the impact of length of orogastric / nasogastric feeding and reflux on early feeding development in preterm infants?	23	23	23	69

E. Voting Form (includes the Long List of 104 questions)



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VOTING FORM

**PRETERM BIRTH AND PREMATURE BABIES:
WHAT DO YOU WANT RESEARCHED?**

Welcome to **stage two** of our preterm birth and premature babies research priority setting exercise. For those who sent us questions in the first stage, thank you very much, your response was fantastic.

Having processed all of the suggestions and ideas, we now need your help to decide which of these are most important.

We would like you to **choose TEN questions**, that you think are the most important from the list below.

You may not see your own question in this list. This is because we have combined and reworded some of the questions.

If you prefer, you may print this survey out then send the paper copy to Seilin Uhm, or contact her for a pre-paid and addressed envelope:

Email: s.uhm@ioe.ac.uk

Address: Social Science Research Unit, Institute of Education, University of London

18 Woburn Square, London WC1H 0NR

Tel: +44(0)20 7612 6532 (Direct) Fax: +44(0)20 7612 6400

This survey is available on-line.

Go to https://www.surveymonkey.com/s/preemie_study or scan
to take part in this way



The closing date for the survey is midnight Friday 13^h of December 2013.



PART ONE - LIST OF UNCERTAINTIES

Please choose your top TEN research questions from the list below.

Make your mark in the 'Vote here' column on the left hand side of the research questions.

Pre-pregnancy or early pregnancy treatments

- Treatments to predict or prevent preterm birth

	Vote here	Question
1.		Which treatments (including diagnostic tests) are most effective to predict or prevent first preterm birth ?

- Treatments to prevent preterm birth in next pregnancy

	Vote here	Question
2.		What treatments can predict reliably the likelihood of subsequent infants being preterm ?
3.		Is treating fibroids during pregnancy effective to reduce the risk of preterm birth?
4.		What treatments are effective to prevent fibroids growing during pregnancy and thus reduce the risk of preterm birth?

- Treatments to prevent [pre-eclampsia](#)

	Vote here	Question
5.		Which treatments are most effective to prevent pre-eclampsia (for example, progesterone , calcium, garlic etc)?
6.		When should women who have pre-eclampsia with mild or moderate hypertension give birth?

Treatments during pregnancy ([antenatal](#))

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- [Screening](#)/early diagnosis of preterm birth

	Vote here	Question
7.		Is screening in the first trimester effective to help prevent preterm birth?
8.		Can screening of the placenta be effective to detect placenta abnormalities associated with preterm birth ?
9.		What methods are most effective to predict risk of preterm birth in order to allocate service provision?
10.		Is routine transvaginal scanning during pregnancy to detect short cervical length , and treatment, cost effective?
11.		Does specialist prenatal care, for women showing signs of preterm birth , improve morbidity and mortality in mother and baby?
12.		Does screening and treatment for Group B Streptococcus help to prevent preterm birth and neonatal morbidity and mortality ?
13.		Are risk scoring systems effective to help predict preterm birth ?
14.		Which treatments are effective in preventing spontaneous preterm birth in women with twin and triplet pregnancies, especially in those at high risk of preterm birth?
15.		What is the effectiveness , practicality and acceptability of chlamydia screening to prevent preterm birth in an antenatal setting?

- Medications or substance intake during pregnancy (incl vitamins)

	Vote here	Question
16.		Are vitamins effective to prevent preterm birth?

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17.		How do stress, trauma and physical workload contribute to the risk of preterm birth , are there effective ways to reduce those risks and does modifying those risks alter outcome ?
18.		What dosage of progesterone is most effective for preventing preterm birth in high risk groups?
19.		Does nutritional deficiency influence the effectiveness of treatments known to be effective for the prevention of preterm birth?

- Information provision and service delivery during pregnancy

	Vote here	Question
20.		What guidance and information is most useful for parents at risk of having preterm infants?
21.		Does education and support, for mothers with increased risk of preterm birth and their families, help to prevent preterm birth?
22.		Which test is most effective to diagnose urinary tract infections in early labour and does early detection and treatment of urinary tract infection affect preterm birth and its outcomes ?
23.		How should healthcare professionals best communicate, including information about possible disabilities, with parents at risk of preterm birth to improve outcomes?

- Length of cervix/cervical [cerclage](#) (stitching)

	Vote here	Question
24.		Does cervical cerclage help to prevent preterm birth?
25.		Does the use of pre-pregnancy diagnostic techniques aimed at diagnosing ' cervical weakness ' in women with a history of

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		preterm birth and/or second- trimester loss assist in the decision to place a history-indicated cerclage and does this influence outcome?
26.		In women who have an incidental finding of a short cervical length , does analysis of amniotic fluid guide who benefits from cervical cerclage ?
27.		Does pessary (progesterone) help to prevent preterm birth?
28.		Should the decision on how best to minimise the risk of recurrent preterm birth in women at risk, either because of poor history of a short or dilated cervix, be 'personalised', based on the clinical circumstances, skill and expertise of the clinical team and, most importantly, the woman's informed choice?

- Other [antenatal](#) Treatments

	Vote here	Question
29.		Is tocolytic therapy effective to prevent preterm birth in multiple pregnancies?
30.		In women threatening preterm labour is maintenance tocolytic therapy effective in improving outcomes of preterm birth?
31.		Which lifestyle changes including gym, bed rest, posture and sexual intercourse are effective to minimise the risk of preterm birth?
32.		What are the benefits and harms of immediate versus deferred delivery of preterm infants with suspected fetal compromise?

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Treatments at birth

- [Premature rupture of membranes \(PROM\)](#)

	Vote here	Question
33.		Does intervening after a specific duration of PROM affect incidence and outcome of preterm birth ?
34.		Which treatments are most effective for PROM
35.		What are the clinical benefits and harms for women and their babies of immediate delivery compared with expectant management for women with preterm pre-labour rupture of the membranes?
36.		What are the risks and benefits of expectant management versus delivery in women whose membranes rupture spontaneously between 34 and 37 weeks gestation ?

- [Caesarean](#) Section

	Vote here	Question
37.		Is birth by caesarean section of benefit to neonatal outcome for late preterm infants?

- Prophylactic corticosteroid therapy in preterm labour (steroids given before/during or after birth)

	Vote here	Question
38.		What are the long-term benefits and risks of multiple courses of antenatal corticosteroids on neonatal morbidity (including early childhood) and mortality ?

- Delayed cord clamping

	Vote here	Question
39.		What is the best time to clamp the umbilical cord for preterm babies?

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- Other perinatal treatments

	Vote here	Question
40.		Is antenatal and intrapartum cardiotocography monitoring of preterm infants beneficial in improving outcomes of preterm birth?
41.		What roles should fathers be offered during preterm labour and preterm birth?
42.		What are the benefits of specialist antenatal care at preterm birth clinics for women at high risk of preterm birth?

Treatments after birth (postnatal) until discharge from hospital

- Initial care and support at birth

	Vote here	Question
43.		Should extremely immature babies be intubated at delivery and surfactant given, or should CPAP be attempted?
44.		What should be included in the care offered to babies during the initial stabilisation after preterm birth?
45.		What is the best treatment for life-threatening lung damage in preterm infants?
46.		Which interventions should be included in a package of respiratory care to optimise developmental outcomes for preterm babies?
47.		Is high flow nasal cannula (HFNC) safe and effective as a form of respiratory support in preterm infants?

- Care and feeding during hospital

	Vote here	Question

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48.		What is the best way to encourage Kangaroo Mother Care more by staff in NICU for parents?
49.		Is community initiation of Kangaroo Mother Care beneficial?
50.		How effective is the use of early onset continuous Kangaroo Mother Care in stabilized preterm infants as an alternative to conventional neonatal care in resource limited settings?
51.		What type of support is most effective at improving breastfeeding in NICU /SCBU/feeding clinics?
52.		What is the impact of length of orogastric / nasogastric feeding and reflux on early feeding development in preterm infants?
53.		Does ad libitum or demand/semi-demand feeding regimen (versus scheduled interval feeding) affect important clinical outcomes for preterm infants and their families?
54.		What is the optimum milk feeding regimen, for preterm infants, including quantity and speed of feeding and use of donor and formula milks?
55.		How does banked preterm milk versus banked term milk compare to promote growth and development in very low birth weight infants?
56.		At what time is it safest to introduce formula milk to preterm infants when expressed breast milk is unavailable?
57.		Does slow advancement of enteral feed volumes help to prevent necrotising enterocolitis in very low birth weight infants?
58.		What is the best method to diagnose feeding problems in preterm infants, including allergies and failure to thrive due to poor feeding?
59.		What are the effects of oral motor treatments versus treatments such as managing flow rate, pacing during oral

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		feeds and thickening of feedings, on pulmonary function in preterm infants?
60.		Which treatments should be included in a care bundle to optimise nutrition, growth and oro-motor development in premature babies with feeding difficulties?
61.		Is breast milk fortifier beneficial for preterm infants?
62.		How is it best to establish oral feeding in preterm infants?
63.		Which treatments are most effective for necrotising enterocolitis in preterm infants?
64.		Can neurodevelopmental care and <i>strong/effective</i> parenting improve quality of life for preterm infants?
65.		Is the newborn individualised development care and assessment program (NIDCAP) effective to improve the quality of care in preterm infants?
66.		Is routine use of ethamsylate effective to improve neurodevelopment and mortality in preterm infants?
67.		Which treatments are most effective to prevent necrotising enterocolitis in preterm infants?

- [Bonding](#) and [attachment](#) of parents and infants

	Vote here	Question
68.		Which treatments improve attachment and bonding and does the promotion of appropriate attachment and bonding improve outcomes?

- Effective Communication/Support to parents

	Vote here	Question
69.		What emotional and practical support should be included in a care bundle that aims to optimise outcomes of preterm birth?

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- Sensory Issues

	Vote here	Question
70.		What are the best ways to optimise the environment in order to improve outcomes (for example cycled light , eye masks, ear muffs or music therapy)?

- Pain Management of Infants

	Vote here	Question
71.		How should morphine or ketamine for ventilated preterm babies be used to optimise outcomes?
72.		How should sucrose be used to optimise outcomes?
73.		Are pharmacological treatments, including analgesia , effective for pain management in preterm infants?
74.		Which non-pharmacological measures relieve pain in the vulnerable group of sick and ventilated preterms?
75.		What is the best way to judge whether a baby is feeling pain (for example, by their face, behaviours or brain activities)?

- Other postnatal treatments during hospital stay

	Vote here	Question
76.		Do preterm babies have better outcomes if their parents have roomed in?
77.		What is role of siblings in caring for their preterm sibling in hospital?
78.		Do parents of preterm infants benefit from an open approach to notes and ward rounds?
79.		What is the benefit of diagnostic testing, including lumbar puncture , for preterm infants?

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80.		How should neonatal transport of preterm babies be done to minimise brain injury?
81.		Does stem cell therapy improve outcomes in preterm babies with evidence of brain injury?
82.		What is the role of therapeutic hypothermia in premature babies?
83.		How can infection in preterm infants be better prevented?
84.		What is the best way to manage early-onset neonatal infection for preterm babies?
85.		What is the clinical and cost effectiveness of intrapartum prophylactic antibiotic benzylpenicillin to prevent early onset neonatal infection?
86.		What are the best methods, including laboratory investigations, to identify risk factors and clinical signs and symptoms to identify babies needing antibiotics for early-onset neonatal infection?
87.		What is the clinical and cost effectiveness of laboratory investigations used individually or in combination to exclude early-onset neonatal infection in babies receiving antibiotics for suspected infection?
88.		What is the optimal duration of treatment in infants receiving antibiotics for confirmed early onset neonatal infections?
89.		How does each step in the care pathway for prevention and treatment of early-onset neonatal infection impact on babies and their families?
90.		What is the clinical and cost- effectiveness of information and support offered to parents and carers of babies who have received antibiotics for suspected or proven early-onset neonatal infection?
91.		Which risk factors for early-onset neonatal infection, symptoms and signs of infection, and laboratory investigations

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		should be used to identify babies who should receive antibiotics?
92.		Is drainage, irrigation and fibrinolytic therapy (DRIFT) an effective treatment in the management of post-haemorrhagic hydrocephalus in preterm infants who may suffer severe disability as a result?
93.		What should be included in the care of jaundice in premature babies to optimize outcomes?

Treatments after birth (postnatal) after discharge from hospital

- End of life care

	Vote here	Question
94.		What should be included in packages of care to support parents (and families) with decisions about continuing or withdrawing life-sustaining care?
95.		What should be included in packages of care to support parents (and families) when a premature baby dies?

- During transition from hospital to home

	Vote here	Question
96.		What should be included in packages of care to support parents and families / carers when a premature baby is discharged from hospital?
97.		Is multi-nutrient fortified breast milk compared with unfortified breast milk more effective for long term growth and development of preterm infants following hospital discharge?
98.		Which nutrients are most effective for growth and development of preterm infants?

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General / Patient Care

	Vote here	Question
99.		Is the UK neonatal care model compared to the Swedish care model more effective for the care of preterm infants ?
100.		What is the effect of partnership working between healthcare professionals and parents on the care of preterm infants ?

Staff Issues

	Vote here	Question
101.		What should healthcare professionals know about preterm birth (staff training about preterm birth)?
102.		What level of training about preterm birth is optimal for midwives?
103.		Do support groups for healthcare professionals involved in the care of preterm babies (and women at risk of preterm birth) improve outcomes for the babies (or the staff)?
104.		What should the role of the specialist neonatal nurse be in the team in order to achieve the best long-term developmental outcomes for infants and their families in neonatal care?

PART ONE – ABOUT YOU (this information helps us understand the background of people who have answered this survey. The information is anonymous. If you prefer, you can skip these questions.)

QUESTION 1 Are you a _____?

(Please tick the one that applies to you)

Service user (parent, family, grandparent, carer etc) – Go to Question 2

Health care professional– Go to Question 3

Both service user and health care professional – Go to Question 4

Other (please specify)_____ – Go to Question 5

QUESTION 2 (Service users only) Are you _____?

- A parent of a preterm baby
- Someone who was born prematurely
- A grandparent of a preterm baby
- A carer of a preterm baby or of a family with a preterm baby
- Another family member of a preterm baby

Other - Please specify _____

Please go to Question 5 now.

QUESTION 3 (Health Care Professionals only)

Please tell us what kind of health care professional you are.

- Midwife Nurse General practitioner Obstetrician
- Neonatologist
- Other medical doctor or surgeon (Please state specialism) _____
- Other - Please specify _____
- Prefer not to say (Please go to Question 5 now)

QUESTION 4 (Health Care Professionals and Service Users)

As you are both a health care professional and service user, please tick the boxes below which apply to you.

- Parent of a preterm baby Someone who was born prematurely
- Grandparent of a preterm baby
- Carer of a preterm baby or of a family with a preterm baby
- Other family member of a preterm baby
- Midwife Nurse General practitioner
- Obstetrician
- Neonatologist
- Other medical doctor or surgeon (Please state specialism) _____
- Other - Please specify _____
- Prefer not to say

Please follow on to Question 5 now.

QUESTION 5 Are you_____?

(Please tick the appropriate option)

Female Male

QUESTION 6 How would you describe your ethnic group?

(Please tick the appropriate option)

White Mixed Asian Black Chinese

Other Ethic Group_____ Prefer not to

say

QUESTION 7 Can you describe the housing that you are currently living in?

(Please select the closest one)

Own property (or have mortgage) Rented accommodation

Living with family or relatives

Other accommodation (please specify)

Prefer not to say

PART THREE You have completed your vote - **thank you for taking part.**

What happens next?

- Your vote will help us to select a shortlist of questions (approx 30) that will be discussed at the workshop, where the ten most important questions for research will be agreed. If you are interested in participating in this workshop, or would like to hear from us about the results of this workshop, please tell us your contact details below (these will be stored securely and not passed on to anyone else.

- We will keep you informed via our website (<http://eppi.ioe.ac.uk/pretermbirth>) and Twitter feed (@PretermBirth).

Title_____
First Name _____
Family Name_____
Address_____
email----- _____

F. Glossary for the voting form (presented with the voting form)

Ad libitum 'without restraint' ie. milk available at all times with quantity and frequency being free choice ([The Medical Dictionary 2013](#)).

Amino acid analysis An analysis of the amino acid components of a protein (Preterm birth priority setting partnership steering group 2013).

Analgesia a deadening or absence of the sense of pain without loss of consciousness ([The Free Dictionary 2013](#)).

Antenatal means before birth – so the care and of the pregnant woman and unborn child before birth ([Merriam-Webster Dictionary 2013](#)).

Antenatal corticosteroids Steroids are given antenatally to mothers where the birth seems likely to occur early. The drug crosses the placenta and causes the baby's lungs to mature for breathing ([Bliss 2009](#))

Attachment is an emotional bond to another person. The central theme of attachment theory is that mothers who are available and responsive to their infant's needs establish a sense of security in their children ([Cherry 2013](#)).

Banked preterm milk - human milk donated by mothers of preterm babies. The milk is collected by mothers of preterm babies who are making more milk than their babies require and these mothers donate to a human preterm milk bank. The milk in the milk bank is screened and given to preterm babies whose mothers are not able to express sufficient milk for their babies. Breast milk from mothers of premature babies has been shown to be different from breast milk from mothers of full term babies (preterm milk has more nutrients in it). (Wikipedia: http://en.wikipedia.org/wiki/Human_milk_banking_in_North_America)

Benefits and Risks/Harms Treatments can have benefits but also harms or risks. Evidence-based medicine seeks to assess the strength of the evidence of risks/harms and benefits of treatments and diagnostic tests. This helps clinicians predict whether a treatment will do more good than harm ([Atkins 2004](#)).

Benzylpenicillin This is an antibiotic, in the group of drugs known as penicillins. It is also known as penicillin G.

Bonding The formation of a close relationship between mother and child especially through frequent or constant association ([Merriam-Webster Dictionary 2013](#)).

Caesarean section is a surgical procedure with incision in the walls of the woman's abdomen and uterus for delivery of a baby or babies ([Merriam-Webster Dictionary 2013](#)).

Cardiotocography - a way of recording the baby's heartbeat and the mother's contractions whilst the baby is in the uterus or womb.

Cervical cerclage is a procedure in which stitches are used to hold the cervix closed—during pregnancy to help prevent premature birth (Mayo Clinic, 2013). The cervix being the lower part of the uterus that opens to the vagina.

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Cervical length is the length of the cervix from the body of the uterus to the tip of the cervix. It is sometimes linked to preterm labour. If you have a short cervix, you might be at increased risk of preterm labour and premature birth (Harms, 2012).

Cervical weakness sometimes called 'incompetent cervix' means your cervix is softer and weaker and the weight of the growing baby puts increased pressure on it ([Baby Center Medical Advisory Board](#))

Chlamydia is a sexually transmitted disease. Chlamydia is the most common in people younger than 25. Many women who have Chlamydia have no signs or symptoms ([March of Dimes 2013](#)).

Clinical outcome is a change in health that is attributable to a healthcare intervention. The measurement of clinical outcomes is important because it enables us to know how effective our services are at delivering treatment and care ([Great Ormond Street Hospital for Children NHS Foundation Trust](#)).

Clofibrate a drug that reduces lipids in the blood serum, used to treat some cardiovascular diseases (Vocabulary Dictionary 2013).

CPAP (Continuous Positive Airway Pressure) A form of treatment used to help a baby's breathing and to reduce the number of apnoeic attacks. (when someone takes a very long pause between their outward and inward breath). Using a CPAP machine, the lungs are expanded by applying a small amount of pressure through small prongs just inside the nose or by a small mask over the nose. In some cases a premature baby may be on and off CPAP for several weeks ([Bliss 2009](#)).

Cycled Light vs continuous light Pregnant women are exposed to variable intensities of light and sound, which induces circadian rhythms for the baby, but after birth preterm babies are often exposed to environments where it is light all the time (on a neonatal unit). Cycled light refers to an environment on a neonatal unit which keeps a rhythm of light and dark ([Morag 2011](#)).

Developmental Care is all about making the baby's surroundings as free of stress as possible. This is done in several ways: reducing the amount of light and noise that the baby is exposed to; in some cases covering the incubator with a sheet or specially made cover; creating a 'nest' to nurse a baby in which makes them feel comfortable and secure; reducing disruption to the baby; infant massage; parent involvement in caring for your baby on the unit – kangaroo care for example ([Bliss 2009](#)).

Drainage, irrigation and fibrinolytic therapy (DRIFT) Bleeding in the brain is a serious complication in babies born prematurely. This procedure aims to remove the blockage and reduce its harmful effects by draining excess cerebrospinal fluid from the brain, washing out the blood and breaking down blood clots using drugs (fibrinolytics) ([National Institute for Health and Care Excellence 2012](#)).

Effectiveness the extent to which specific clinical interventions when deployed in the field for a particular patient or population do what they are intended to do, that is, maintain and improve health and secure the greatest possible health gain ([Graham 2009](#)).

Enteral feeding or tube **feeding** is a medical device used to provide nutrition to patients who cannot obtain nutrition by mouth, are unable to swallow safely, or need nutritional

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supplementation. The state of being fed by a feeding tube is called **gavage, enteral feeding** or **tube feeding**. (Guenter, 2001)

Ethamsylate is a drug that decreases blood loss in certain clinical situations. The potential to reduce bleeding suggests ethamsylate may have a role to play in reducing intraventricular haemorrhage in preterm infants ([Hunt 2003](#)).

Expectant management (also known as 'watchful waiting') A hands-off management philosophy in which certain conditions are closely monitored, but treatment withheld until symptoms either appear or the situation changes. Active management is the opposite of expectant management and is when treatment is given straight away.

Fibroids are non-cancerous growths that occur in or around the womb (uterus). The growths are made up of muscle and fibrous tissue and can vary in size ([NHS Choices 2013](#)).

Gestation the time period of carrying the baby (Wikipedia).

High flow nasal cannula (HFNC) are small, thin, tapered plastic tubes used to deliver oxygen or blended oxygen and air at flow rates of > 1L/minute ([Wilkinson 2011](#)).

History-indicated cerclage insertion of a cerclage as a result of factors in a woman's obstetric or gynaecological history which increase risk of spontaneous second-trimester loss or preterm delivery ([Royal College of Obstetricians & Gynaecologists 2011](#)).

Hypertension is a chronic medical condition in which the blood pressure is raised. This requires the heart to work harder than normal to circulate blood through the blood vessels. Blood pressure is summarised by two measurements, systolic and diastolic, which depend on whether the heart muscle is contracting (systole) or relaxed between beats (diastole) and equate to a maximum and minimum pressure, respectively.(Wikipedia)

Immediate versus deferred delivery refers to when a baby is delivered immediately compared to waiting for a long as is thought to be safe (deferred).

Intervention The act or fact or a method of interfering with the outcome or course especially of a condition or process ([Merriam-Webster Dictionary 2013](#)).

Intrapartum occurring chiefly with reference to a mother during the act of birth ([Merriam-Webster Dictionary 2013](#)).

Intrapartum antibiotic prophylaxis Antibiotics given during labour aimed at preventing infection ([National Institute for Health and Care Excellence 2012](#)).

Intubated Intubation is the process of inserting a tube into the mouth and then into the airway. This is done so the baby can be placed on a ventilator to assist with breathing ([Patient.co.uk 2013](#)).

Intra-ventricular haemorrhage (IVH) This is a problem which affects babies born prematurely where there is bleeding into the ventricles of the brain. An IVH can be serious but in many cases it causes no long-term problems ([Bliss 2009](#)).

Jaundice-related neonatal morbidity – a sick baby due to jaundice (a condition where too much bilirubin in the blood makes the skin and whites of the eyes go yellow)

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Kangaroo Care is the practice of holding your baby on your bare chest with a blanket draped over your baby's back. This skin-to-skin contact benefits both you and your baby ([March of Dimes 2013](#)).

Ketamine A drug which is used as a for pain relief and for anaesthesia on the neonatal unit, it causes less suppression of breathing than other similar drugs (Preterm birth priority setting partnership steering group 2013)

Long-term use of sucrose According to The WHO Reproductive Health Library (RHL), "Administration of oral sucrose sugary liquid (in dosages of 0.5–2 ml of 12%–50% solution) before painful procedures is effective in providing pain relief in both term and preterm infants. However, the longer-term effects of sucrose, especially for extremely premature babies, who are at the greatest risk of receiving repeat doses, is not known." (Murki et al, 2011)

Long-term ventilation Assisted ventilation is used to support breathing until the patient's respiratory efforts are sufficient. For preterm infants, ventilation may be required during immediate care of the infant or during prolonged periods of respiratory failure (<http://emedicine.medscape.com/article/979268-overview>)

Lumbar puncture (LP) If there is evidence of a severe infection, doctors may want to take a sample of fluid that surrounds the spinal cord. This fluid flows down from the brain, so analysing it should show if the infection is present in this vital part of the nervous system ([Bliss 2009](#)).

Magnesium maintenance therapy This is one of the types of tocolytic therapy (drugs to reduce contractions of the uterus) used after an episode of threatened preterm labour in an attempt to prevent the onset of further preterm contractions (Han et al, 2013).

Morphine is a strong opiate drug (extracted from the opium poppy) that is used to relieve severe pain. It is a habit-forming drug which can lead to drug dependency (Wikipedia: <http://en.wikipedia.org/wiki/Morphine>).

Music therapy Researchers have speculated that being born prematurely could be traumatic (from an acoustic perspective) for two reasons (1) Baby being separated from the sound of mother's heartbeat (2) Baby 'plunged' into the noisy environment of the neonatal care unit ([NHS Choices 2013](#)).

Necrotising enterocolitis (NEC) When a section of the wall of the intestine is swollen or inflamed because of damage to the lining. This is often linked to a period in which the blood flow to the gut wall has been reduced. The abdomen may swell up, and blood is passed through the bowels ([Bliss 2009](#)). This is a major cause of mortality and morbidity for preterm babies (Preterm birth priority setting partnership steering group 2013).

Neonatal mortality is death during the first 28 days after birth ([March of Dimes 2010](#)).

Neonatal morbidity a disorder in the neonate, child or family which occurs as a result of adverse influences or treatments acting either on the fetus during pregnancy and/or infant during the first four weeks of life ([Australian Government National Health & Medical Research Council 1995](#)).

Neuro-development care the process of developmental care involves creating an environment for the infant that minimises stress while providing developmentally appropriate experience for the infant and family ([Neonatal Handbook 2010](#)).

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Neonatal Intensive Care Unit (NICU) a neonatal intensive care unit specializing in the care of ill or prenatal newborn babies (Preterm birth priority setting partnership steering group 2013)

Hyperbilirubinemia results from a higher-than-normal level of bilirubin in the blood. **Neonatal hyperbilirubinaemia**, where the newborn's liver is not able to properly process the bilirubin causing **jaundice** <http://en.wikipedia.org/wiki/Bilirubin>. **Non-haemolytic hyperbiliubinaemia** is when there is jaundice without any red cell breakdown (Preterm birth priority setting partnership steering group 2013).

Non-pharmacological is an approach to pain with techniques other than drugs / medication. It aims to prevent suffering by enhancing the psycho-emotional and spiritual components of care ([Medscape 2013](#)).

Nutritional deficiency an inadequate supply of essential nutrients (as vitamins and minerals) in the diet resulting in malnutrition or disease ([Merriam-Webster Dictionary 2013](#)).

Oro-motor development / Oral motor interventions These are methods designed to improve feeding. The focus of most interventions is to increase functional responses to pressure and movement and control of movements for the lips, cheeks, jaw and tongue ([Lessen 2011](#)).

Orogastric / nasogastric feeding and reflux Nasogastric feeding is when a baby is fed through a nasogastric tube (a tube with a narrow bore tube passed through the passages of the nose) into the stomach (Preterm birth priority setting partnership steering group 2013).

Pessary (progesterone) Progesterone is a hormone that stops the uterus from contracting and is involved in maintaining pregnancy (Dodd et al, 2009). A pessary is a medicated vaginal suppository such as progesterone put into the vagina where it dissolves and is absorbed ([The Free Dictionary 2013](#)).

Phototherapy is exposure to daylight or to specific wavelengths of light (Wikipedia: http://en.wikipedia.org/wiki/Light_therapy).

There are two types of phototherapy: (1) **Conventional phototherapy**: where baby is placed under halogen, LED or fluorescent lamp with their eyes covered (2) **Fibreoptic phototherapy**: where baby lies on a blanket that incorporates fibreoptic cables. Light travels through the fibreoptic cables and shines onto baby's back ([NHS Choices 2012](#)).

Placenta The placenta attaches to the wall of the uterus (womb) and supplies the baby with food and oxygen through the umbilical cord ([March of Dimes 2012](#)).

Pre-eclampsia Occurs in about 1 in 14 pregnancies and causes around a third of all premature births. It can be dangerous, particularly if it develops rapidly. The main symptoms are headaches and swollen feet, which are associated with high blood pressure. Although bed-rest can help, the only way to stop pre-eclampsia is to deliver the baby early ([Bliss 2009](#)).

Premature rupture of membranes Preterm PROM is the rupture of membranes prior to the onset of labour in a woman who is at less than 37 weeks' gestation ([Savitz, Ananth et al. 1997](#)).

Preterm birth / preterm labour A baby born before reaching 37 completed weeks ([Bliss 2009](#)).

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Progesterone is a hormone. It plays a key role during pregnancy. In early pregnancy, the hormone helps your uterus grow and keeps it from contracting. In late pregnancy, progesterone helps your breasts get ready to make breast milk ([March of Dimes 2013](#)).

Psychosocial interventions These target the psychological and social factors that cause and maintain difficulties ([Clinical Psychology Associates - Psychosocial Interventions 2013](#)).

PVL Periventricular Leukomalacia. If parts of the brain are deprived of oxygen and blood flow for too long, the brain cells may die and be replaced by fluid cysts. These can be seen in the ultrasound examinations (ultrasound scan) of the baby's brain and depending on the area affected, may indicate future developmental problems ([Bliss 2009](#)).

Resuscitation This is to revive from death or unconsciousness by providing first aid procedures ([Bliss 2009](#)).

Risks please see 'benefits and risks/harms' definition above.

Risk scoring systems a quantitative method used to screen populations to identify persons at increased risk of developing a specific adverse health condition. ([Shiono 1993](#)).

Screening To test or examine for the presence of something ([Merriam-Webster Dictionary 2013](#)).

Sensory Care / Sensory stimulation The physical environment of the neonatal intensive care unit (NICU) can influence the development of neonates. Examples of sensory care include tactile stimulation, kangaroo care, early exposure to mother's scent, noise assessments, avoiding exposure of infant to direct light ([Laudert 2007](#)).

Service Provision – providing a service

Short uterine anomaly A small number of women have a uterus that differs in structure from normal ([Babycentre Medical Advisory Board 2013](#)).

Specialist prenatal and neonatal care is the care provided for newborn babies in neonatal units who need extra care ([National Institute for Health and Care Excellence 2012](#)).

Spontaneous preterm birth a birth as a result of spontaneous preterm labour (before 37 weeks) which is not medically induced (Preterm birth priority setting partnership steering group 2013)

Stem cell therapy is an intervention strategy that introduces new adult stem cells into damaged tissue in order to treat disease or injury (Lindvall, 2006). Stem cells can be collected from the umbilical cord at birth (Stem cell harvesting).

Stress-reduction techniques refers to various strategies and therapies that are available that help with relaxation and stress management (thefreedictionary.com).

Surfactant A mixture of chemicals that prevent the lungs from collapsing when the baby breathes out. Production of surfactant in the lungs starts at about 24 weeks but it is not well developed before 36 weeks gestation. This can be the cause of Respiratory Distress Syndrome (RDS). Replacement surfactant can be given as a liquid into the lungs of the premature baby ([Bliss 2009](#)).

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Swedish care model, The Swedish healthcare system is mainly [government-funded](#) and decentralized, although private health care also exists. The health care system in Sweden is financed primarily through taxes levied by county councils and municipalities(Wikipedia: http://en.wikipedia.org/wiki/Healthcare_in_Sweden).

Thickening of feeds Thickening agents added to breast milk or formula aimed at helping milk to stay in the stomach ([Bird 2012](#)).

Tocolytic therapy (tocolysis) also known as anti-contraction medications or 'labour repressants' are medications used to suppress premature labour ([deHeus et al 2009](#)).

Total body hypothermia a below normal temperature of the body, under 36.6C (Medline Plus).

Transporting babies Transport of premature babies shortly after birth, usually to receive more intensive or specialist care than available at the unit where the baby was born. Usually performed by a special team of neonatal doctors and nurses in the UK([Bull 2013 revised ed](#)).

Transvaginal scanning/ultrasound is an imaging technique used to create a picture of the genital tract in women. The hand-held device that produces the ultrasound waves is inserted directly into the vagina, close to the pelvic structures, thus often producing a clearer and less distorted image than obtained through transabdominal ultrasound technology, where the probe is located externally on the skin of the abdomen. (McGraw-Hill, 2002)

Trimester Pregnancy lasts about 40 weeks, counting from the first day of your last normal period. The weeks are grouped into three trimesters of about three months each (womenshealth, Office on Health, US Dept of Health and Human Services, 2010).

Umbilical cord clamping The umbilical cord is clamped before it is cut to help seal off the open blood vessels in the cord ([Weeks 2007](#)).

Universal pre-discharge transcutaneous bilirubin screening some studies have suggested that universal predischarge bilirubin screening prevents the development of very high bilirubin levels ([Medscape 2013](#)).

Urinary tract infections is an infection in any part of your urinary system – your kidneys, ureters, bladder and urethra. Most infections involve the lower urinary tract – the bladder and the urethra ([The Mayo Clinic 2013](#)).

Validated pain measures Validation is the process by which any data collection instrument is assessed for its dependability ([Howard 2008](#)).

G. References of glossary (presented with the voting form)

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H. The process of developing top fifteen priorities into the final wording

Rank 1. Which interventions are most effective to predict or prevent preterm birth?

This research question was raised by 23 service users and 10 health care professionals from the survey. Because the scope of the question was too wide, the steering group considered to remove it from the long list. However, the steering group decided to include it because the number of respondents, who raised this question was the biggest for one specific question. The voting outcomes suggested that more than 40% of voters selected this question as one of their top ten priorities. Amongst 219 voters, health care professionals supported this question strongly (106 votes) than any other group (service users=84, both=29). This question remained as a top priority throughout all sessions at the Final Workshop. The STEERING GROUP decided to use the word 'treatment' instead of 'intervention' when they revised the wording prior to the public voting, because they assumed that 'treatment' would be more comprehensible for the wider public. They also added 'including diagnostic test' in the brackets, to highlight that the question is including interventions to prevent preterm birth. During the Final Workshop, however, the participants preferred 'intervention' to 'treatment', because it would be more inclusive and less limited. They removed the description of 'diagnostic test', to shorten the research question.

Rank 2. How can infection in preterm babies be better prevented?

This question was pointed out by both service users and health care professionals. Although it was raised by a small number of participants, it gained many votes (N=93) from both service users (N=51), health care professionals (N=42) and people, who were both health care professionals and service users (N=10). It was on the seventh place at the voting stage. During the Final Workshop, it moved up to the third place in the morning as participants of four small groups prioritised it. In the afternoon, the topic gained stronger support from all three groups again.

Rank 3. Which interventions are most effective to prevent necrotising enterocolitis in premature babies?

There were two questions on necrotising enterocolitis (NEC) in the voting form: one was about preventing NEC and another one was about treating it. This was because it was considered that they were completely different questions. The question about 'preventing NEC' was identified by a multiple number of sources: service users, health care professionals and researchers. While this question was very popular from both service users and health care professionals at the voting stage (overall ninth place), it gained more health care professionals (N=45) than service users (N=33). In the morning at the Final Workshop, it was the second popular question after the general prevention question. At the end of the day, it moved down to the third place but remained as an immensely popular question, which showed different pattern to the similar question on 'treating NEC'. To highlight the difference between the two questions, the workshop participants agreed to highlight and underline the word ('to prevent', and 'to treat') in each question.

Rank 4. What is the best treatment for lung damage in premature babies?

This question was raised by an equal number of service users (N=3) and health care professionals (N=3). At the voting stage, it also showed a balanced number of votes from both service users (N=31) and health care professionals (N=25). Overall, it was on the 20th place after the voting stage so it was not the question, which attracted all the voters. However, it was considered as one of the most important questions by workshop participants consistently throughout the Final Workshop. The workshop participants removed the wording 'life threatening', to be more inclusive and to shorten the question.

Rank 5. What should be included in packages of care to support parents and families or carers when a premature baby is discharged from hospital?

This question was raised by service users only but attracted many them (N=71). On the contrary, no health care professionals pointed out the importance of care packages at discharge and received comparatively less votes (N=19) from the health care professionals. However, some health care professionals, who had personal experiences of preterm birth, rated this question importantly. Therefore, it was on the overall sixth place after the voting. It was treated as an important question consistently during the Final Workshop.

Rank 6. What is the optimum milk feeding strategy and guidance (including quantity and speed of feeding and use of donor and formula milk) for the best long-term outcomes of premature babies?

There were many questions raised by service users and health care professionals on feeding and nutrition. These questions were grouped into three categories before they were sent out to service users: a. quantity, and speeding

of feeding for formula milk (question number 54 from the voting form), b. right timing for introducing formula milk (question number 56 from the voting form), and concerns on general nutrition for growth development (question number 98 from the voting form). All three questions gained some votes from both service users and health care professionals however none of them were included in the top ten based on the voting outcomes. Prior to the Final Workshop, the Steering group decided to combine all three questions and reworded the question, so it could include all three questions. At the final meeting, this question remained in the top sixth to seventh places consistently. The final workshop participants, who were representing service users' perspective, raised that the word 'regimen' might be less friendly, so changed to the word 'strategy (or guidance)'. Also they added 'for the best long-term outcomes', to enhance the clarity of the question.

Rank 7. What is the best way to judge whether a premature baby is feeling pain (for example, by their face, behaviours, or brain activities)?

This question was originally identified by more health care professionals, particularly neonatal nurses, and researchers rather than service users. However, when it was sent out for voting, more service users voted for it. It was on the 14th place after voting. When the question was brought to the Final meeting it was moved to 6-7th places.

Rank 8. Which treatments are most effective to prevent early onset pre-eclampsia?

Many service users (N=24) asked 'what could prevent pre-eclampsia?' While this question could gain some votes from health care professionals (N=41),

it attracted more service users (N=61). This question was in the fifth place after the voting but slightly moved down to the 8th place during the Final Workshop.

Rank 9. What emotional and practical support improves attachment and bonding does the provision of such support improve outcomes for premature babies and their families?

This question was based on two different questions: a. emotional and practical support (question number 69 from the voting form) and b. issues on attachment and bonding (question number 68 from the voting form).

9.a. Emotional and practical support (Q69)

This question was an outcome of a multiple number of questions about care and support. Many service users and health care professionals acknowledged the importance of this question, highlighting the importance of both emotional and practical support towards infants and families. It was raised by a largest number of service users (N=27) and many health care professionals (N=15) at the identification stage. At the voting stage the question could attract some service users (N=32) but not many health care professionals (N=15). It was on the 33rd place after the voting but included as a top 30 after merging questions on feeding.

9.b. Issues on attachment and bonding (Q68)

This question was raised by service users or health care professionals, who had a personal experience with preterm birth only. No health care professionals mentioned this topic from the survey, and majority of voters were service users for this topic. After the voting, it was on the 25th place so included for the Final Workshop.

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At the Final Workshop, above two questions (Q69 and Q68) were both included within the top ten after the small ground discussion in the afternoon session. However, participants decided to merge the two questions at the end stage of the whole group discussion. There were some service users, who expressed their concerns on the merger because the questions could be very different. However, the whole group decided to merge and present it as one question so that they could include one more question. A clinical psychologist worked on wording on the question after the workshop but it was approved by the steering group members of the partnership. The original wording of the questions in the Long List (voting form) were; 'what emotional and practical support should be included in a care bundle that aims to optimise outcomes of preterm birth? (Q69)', and 'which treatments improve attachment and bonding and does the promotion of appropriate attachment and bonding improve outcomes? (Q68)'

Rank 10. Which treatments are most effective for preterm premature rupture of membranes?

This question was not raised by many respondents but came from a multiple number of sources: service users, health care professionals, researchers and clinical guidance. At the voting stage it attracted many service users and some health care professionals, so it was on the 13th place based on the number of votes. During the Final Workshop, it was in the 10th to 11th places depending on the timing of the workshop. Because it was agreed to select only ten research questions in the beginning of the workshop, this question was in the marginal place. It was included within the top ten because above two questions on attachment/bonding (Q69) and emotional/practical support (Q68) were merged.

Rank 11. When is the best time to clamp the umbilical cord in preterm birth?

It was one raised by an equal number of service users and health care professionals. It also gained similar number of votes from both groups. After the voting, it was on the 17th place. When the question was brought into the Final Workshop, this question was just outside the top ten. As the workshop participants decided to include all 15 questions, this question could be published.

Rank 12. What type of support is most effective at improving breastfeeding for premature babies?

This question was raised by both service users and health care professionals and both groups voted for this question. There was a suggestion to combine this question with formula milk question. It was in the 14th place after the voting but move up slightly during the Final Workshop. Workshop participants acknowledged that this question on breastfeeding was important to health care professionals and service users but decided to not to move it to the higher rank because there are many on-going campaigns on breastfeeding. There were lengthy discussions on this topic to decide whether this topic is 'true uncertainty' or 'known unknown'. They concluded that it would not be a true uncertainty for the infants born after 37 weeks of pregnancy, but it is still an unanswered question for the preterm infants. Therefore, they agreed to inset the wording 'preterm infants'. They inserted the wording 'preterm born infants' in the rank 15 question with the similar reason.

Rank 13. Which interventions are most effective to treat necrotising enterocolitis in premature babies?

This was the second question on necrotising enterocolitis (NEC) but on treatment. This question was raised by service users and health care professionals. At the voting stage, it was more popular among health care professionals than service users. This question was on the 23rd place based on the number of voting but moved up during the final prioritisation process at the workshop.

Rank 14. Does specialist antenatal care for women at risk of preterm birth improve outcomes for mother and baby?

This question was identified by health care professionals only but both health care professionals and service users supported the question strongly. After the voting, it was on the 11th place but moved down to the 14th during the final prioritization stage. The original wording for the population in the question was, 'women showing signs of preterm birth'. However, it was raised by both service users and health care professionals that some women might not show any sign of preterm birth but still have risks. Therefore, it was changed to 'women at risk' instead of 'women showing signs'.

Rank 15. What are the best ways to optimise the environment (such as light and noise) in order to improve outcomes for premature babies?

While some service users identified this research question, it was mainly raised by health care professionals working at neonatal units. It was also found from research recommendations. Although this question was raised by mainly health care professionals, it was supported by service users rather than health care professionals. Health care professionals with individual experiences with preterm birth also strongly supported this question. It was in the 26th place based

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on the number of votes but moved up to the 26th place after the Final Workshop.

The workshop participants added the wording 'preterm infants' to highlight the fact that it is an unanswered area for preterm birth. They the wording 'preterm infants' was changed to 'premature babies' to enhance readability.

I. Search term combinations

PubMed search terms

(((((Infant[tiab] OR "Newborn"[tiab] OR "newborns"[tiab] OR "infants"[tiab] OR baby[tiab] OR babies[tiab] OR birth[tiab] OR neonates[tiab] OR neonate[tiab]) AND ("very low birth weight"[tiab] OR "VLBW"[tiab] OR "extremely low birth weight"[tiab] OR "ELBW"[tiab] OR "very low birthweight"[tiab] OR "extremely low birthweight"[tiab] OR "Very-low-birth-weight"[tiab] OR "very low birth-weight"[tiab] OR "extremely-low-birth-weight"[tiab] OR "extremely low birth-weight"[tiab] OR "preterm"[tiab] OR "pre-term"[tiab] OR "Premature"[tiab] OR "prematurity"[tiab])) OR (((("premature birth"[MeSH Terms]) OR "infant, low birth weight"[MeSH Terms]) OR "infant, premature"[MeSH Terms]) OR "infant, premature, diseases"[MeSH Terms])) AND ("Review"[Publication Type] OR "meta-analysis"[tiab] OR "metaanalysis"[tiab] OR "meta analysis"[tiab] OR "Search strategy"[All Fields] OR (("search"[tiab] AND ("literature"[tiab] OR "database"[tiab] OR "bibliographic"[tiab] OR "comprehensive"[tiab] OR "extensive"[tiab] OR "exhaustive"[tiab] OR "purposive"[tiab] OR "representative"[tiab] OR "synthesis"[tiab] OR "synthesise"[tiab] OR "systematic"[tiab])) OR (("Review"[tiab] AND (systematic[tiab] OR evidence[tiab] OR "Meta regression"[tiab] OR "meta synthesis"[tiab] OR "meta- synthesis"[tiab] OR "meta analysis"[tiab] OR metaanalysis[tiab] OR meta-analysis[tiab] OR literature[tiab] OR metanalysis[tiab] OR Metaregression[tiab] OR "Meta-regression"[tiab] OR "Methodological overview"[tiab] OR "Methodologically overview"[tiab] OR "pooled analysis"[tiab] OR "pooled data"[tiab] OR "Quantitative overview"[tiab] OR effectiveness[tiab] OR effects[tiab] OR synthesis[tiab] OR integrated[tiab] OR mapping[tiab] OR methodological[tiab] OR methodologically[tiab] OR intervention[tiab] OR quantitative[tiab] OR research integration[tiab])) OR (("systematic"[tiab] AND ("overview"[tiab] OR "synthesis"[tiab])) OR "review literature as topic"[MeSH Terms]))) NOT ("animals"[MeSH Terms] NOT ("humans"[MeSH Terms] AND "animals"[MeSH Terms]))

Appendices

British Nursing Index

Subject Heading - Neonates : Birthweight

[Used for] Low Birth Weight,

Neonates Premature,

Premature Babies,

Preterm Babies

1. (very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature or Prematurity).mp. [mp=title, abstract, heading words]

2. (Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate).mp. [mp=title, abstract, heading words]

3. Neonates : Birthweight/

4. 1 and 2

5. 3 or 4

6. (meta-analysis or metaanalysis or meta analysis or Search strategy).mp. [mp=title, abstract, heading words]

7. (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)).mp. [mp=title, abstract, heading words]

8. (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration)).mp. [mp=title, abstract, heading words]

9. (systematic and (overview or synthesis)).mp. [mp=title, abstract, heading words]

10. 6 or 7 or 8 or 9

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11. 5 and 10

▼ Search History (11 searches) (Click to close)			
<input type="checkbox"/>	# ▲	Searches	Results
<input type="checkbox"/>	1	(very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature or Prematurity).mp. [mp=title, abstract, heading words]	1618
<input type="checkbox"/>	2	(Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate).mp. [mp=title, abstract, heading words]	12699
<input type="checkbox"/>	3	Neonates : Birthweight/	1144
<input type="checkbox"/>	4	1 and 2	1432
<input type="checkbox"/>	5	3 or 4	1711
<input type="checkbox"/>	6	(meta-analysis or metaanalysis or meta analysis or Search strategy).mp. [mp=title, abstract, heading words]	321
<input type="checkbox"/>	7	(search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)).mp. [mp=title, abstract, heading words]	139
<input type="checkbox"/>	8	(Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration)).mp. [mp=title, abstract, heading words]	8540
<input type="checkbox"/>	9	(systematic and (overview or synthesis)).mp. [mp=title, abstract, heading words]	60
<input type="checkbox"/>	10	6 or 7 or 8 or 9	8818
<input type="checkbox"/>	11	5 and 10	113

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EMBASE

Subject Heading -

systematic review

[Used For]

review, systematic

premature labor

[Used For]

labor, premature

obstetric labor, premature

premature delivery

premature labour

preterm birth

preterm delivery

preterm labor

1. (((very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature or Prematurity) and (Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate)) or premature labor).ot,hw,ab,kw.

2. (meta-analysis or metaanalysis or meta analysis or Search strategy or (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)) or (systematic and (overview or synthesis)) or (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration))).ot,hw,ab,kw.

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3. "systematic review"/

4. 1 and (2 or 3)

5. limit 4 to human

HMIC

Controlled terms - premature babies/ or premature births/

1. premature babies/ or premature births/
2. ((very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature or Prematurity) and (Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate)).ab,hw,ti.
3. (1 or 2) and (systematic reviews or meta analysis or (meta-analysis or metaanalysis or meta analysis or Search strategy or (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)) or (systematic and (overview or synthesis)) or (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration))))).ab,hw,ti.

37 results

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MEDLINE

1. ((very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature or Prematurity) and (Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate)).ab,hw,ti.
 2. (meta-analysis or metaanalysis or meta analysis or Search strategy or (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)) or (systematic and (overview or synthesis)) or (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration))).ab,hw,ti.
 3. Premature Birth/
 4. "Review Literature as Topic"/
 5. (1 or 3) and (2 or 4)
 6. limit 5 to humans
- 5706 results

PyscINFO

1,806 to May Week 2 2011

1. ((very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature or Prematurity) and (Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate)).ab,hw,ti.
2. (meta-analysis or metaanalysis or meta analysis or Search strategy or (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)) or (systematic and (overview or synthesis)) or (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview

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or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration))).ab,hw,ti.

3. premature birth/

4. "literature review"/ or meta analysis/

5. (1 or 3) and (2 or 4)

6. limit 5 to human

SPP

1. ((very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature or Prematurity) and (Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate)).ab,hw,ti.

2. (meta-analysis or metaanalysis or meta analysis or Search strategy or (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)) or (systematic and (overview or synthesis)) or (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration))).ab,hw,ti.

3. 1 and 2

18 results from 3

3 results were selected

Cochrane Library

#1 ((very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature

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or Prematurity) and (Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate)):ti,ab,kw 6904

- #2 MeSH descriptor Infant, Premature, Diseases explode all trees 1943
- #3 MeSH descriptor Infant, Premature explode all trees 2345
- #4 MeSH descriptor Premature Birth explode all trees 211
- #5 MeSH descriptor Infant, Low Birth Weight explode all trees 1586
- #6 (#1 OR #2 OR #3 OR #4 OR #5) 7511
- #7 (meta-analysis or metaanalysis or meta analysis or Search strategy or (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)) or (systematic and (overview or synthesis)) or (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration))):ti,ab,kw 31635
- #8 MeSH descriptor Review Literature as Topic explode all trees 96
- #9 (#6 AND (#7 OR #8)) 664

DARE/HTA

- 1 (((very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature or Prematurity) and (Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate))) 963
- 2 MeSH DESCRIPTOR Premature Birth EXPLODE ALL TREES53
- 3 MeSH DESCRIPTOR Infant, Low Birth Weight EXPLODE ALL TREES 94
- 4 MeSH DESCRIPTOR Infant, Premature, Diseases EXPLODE ALL TREES 95
- 5 #1 OR #2 OR #3 OR #4 979
- 6 MeSH DESCRIPTOR Infant, Premature EXPLODE ALL TREES 139
- 7 #5 OR #6 979









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8 MeSH DESCRIPTOR Review Literature as Topic EXPLODE ALL TREES 52

9 (meta-analysis or metaanalysis or meta analysis or Search strategy or (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)) or (systematic and (overview or synthesis)) or (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration))) 29747

10 #7 AND (#8 OR #9) 840

CINAHL

Search ID#	Search Terms	Search Options	Actions
<input type="checkbox"/> S8	 S3 and S6	Search modes - Boolean/Phrase	View Results (959) View Details Edit
<input type="checkbox"/> S7	 S3 and S6	Search modes - Boolean/Phrase	View Results (959) View Details Edit
<input type="checkbox"/> S6	 S4 or S5	Search modes - Boolean/Phrase	View Results (67132) View Details Edit
<input type="checkbox"/> S5	 TI ((meta-analysis or metaanalysis or meta analysis or Search strategy or (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)) or (systematic and (overview or synthesis)) or (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression ...	Search modes - Boolean/Phrase	View Results (63643) View Details Edit
<input type="checkbox"/> S4	 (MH "Systematic Review")	Search modes - Boolean/Phrase	View Results (8121) View Details Edit
<input type="checkbox"/> S3	 S1 or S2	Search modes - Boolean/Phrase	View Results (13157) View Details Edit
<input type="checkbox"/> S2	 AB ((((very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature or Prematurity) and (Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate)))) or TI ((((very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or ex ...	Expanders - Apply related words Search modes - Boolean/Phrase	View Results (10503) View Details Edit
<input type="checkbox"/> S1	 (MM "Childbirth, Premature") OR (MM "Infant, Premature") OR (MM "Infant,	Search modes - Find all my search terms	View Results (7906) View Details Edit

959 S7 S3 and S6 Search modes - Boolean/Phrase Interface - EBSCOhost

Search Screen - Advanced Search

Database - CINAHL 959 S6 S4 or S5 Search modes - Boolean/Phrase Interface - EBSCOhost

Search Screen - Advanced Search

Database - CINAHL 67132 S5 TI ((meta-analysis or metaanalysis or meta analysis or Search strategy or (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)) or (systematic and (overview or synthesis)) or (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration)))

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analysis or literature or metaanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration)))) or AB ((meta-analysis or metaanalysis or meta analysis or Search strategy or (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)) or (systematic and (overview or synthesis)) or (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration)))) Search modes - Boolean/Phrase Interface - EBSCOhost Search Screen - Advanced Search

Database - CINAHL 63643 S4 (MH "Systematic Review") Search modes - Boolean/Phrase Interface - EBSCOhost Search Screen - Advanced Search

Database - CINAHL 8121 S3 S1 or S2 Search modes - Boolean/Phrase Interface - EBSCOhost Search Screen - Advanced Search

Database - CINAHL 13157 S2 AB ((((very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature or Prematurity) and (Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate)))) or TI ((((very low birth weight or VLBW or extremely low birth weight or ELBW or very low birthweight or extremely low birthweight or Very-low-birth-weight or very low birth-weight or extremely-low-birth-weight or extremely low birth-weight or Preterm or pre-term or Premature or Prematurity) and (Infant or Newborn or Newborns or Infants or Baby or Babies or Birth or neonates or Neonate)))) Expanders - Apply related words

Search modes - Boolean/Phrase Interface - EBSCOhost Search Screen - Advanced Search

Database - CINAHL 10503 S1 (MM "Childbirth, Premature") OR (MM "Infant, Premature") OR (MM "Infant, Premature, Diseases+") Search modes - Find all my search terms Interface - EBSCOhost

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- [#24](#) Birth
- [#23](#) Babies
- [#22](#) Baby
- [#21](#) Infants
- [#20](#) Newborns
- [#19](#) Newborn
- [#18](#) (Infant)
- [#17](#) [#1 or #2 or #3 or #4 or #5 or #6 or #7 or #9 or #10 or #11 or #12 or #14 or #15](#)
- [#16](#) (very low birth weight)
- [#15](#) pre-term
- [#14](#) Prematurity
- [#13](#) Pretermpre-term
- [#12](#) Preterm
- [#11](#) extremely low birth-weight
- [#10](#) extremely-low-birth-weight
- [#9](#) very low birth-weight
- [#8](#) Very-low-birth-weight
- [#7](#) extremely low birthweight
- [#6](#) very low birthweight
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2. (systematic reviews / meta analysis / (meta-analysis / metaanalysis / meta analysis / Search strategy / (search and (literature or database or bibliographic or comprehensive or extensive or exhaustive or purposive or representative or synthesis or synthesise or systematic)) or (systematic and (overview or synthesis)) or (Review and (systematic or evidence or Meta regression or meta synthesis or meta-synthesis or meta analysis or metaanalysis or meta-analysis or literature or metanalysis or Metaregression or Meta-regression or Methodological overview or Methodologically overview or pooled analysis

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or pooled data or Quantitative overview or effectiveness or effects or synthesis or integrated or mapping or methodological or methodologically or intervention or quantitative or research integration))))).ab,hw,ti.

J. Taxonomy from systematic mapping

1st degree	2nd degree	3rd degree	4th degree
population	Babies	born less than 28 weeks	
		born 28 to less than 32 weeks	
		born 32 to less than 37 weeks	
	Mothers	Emotional distress	Supervision of child
			The child's peer relationship
			The child's self-esteem
			Impact on the mother's role in the family due to her absence
		Strain and compromised sense of mastery	
		Health-related Quality of Life (QoL)	
	Parents	Difficulty in employment	
		Gender role differences	

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		Parents' marital relationship	
	Families	Family stress at different ages	
		The impact of the child's difficulties on family routine	
		Limitation in family social life	
		Financial burden	
	Siblings	Decreased attention	
	Carers		
health Conditions	mortality	Neonatal period (28days)	
		Infancy (first year)	
	Acute complications	Lungs and respiratory system	Respiratory distress syndrome (RDS)
			Bronchoplummonary Dispalsia(BPD) and Chronic Lung Disease(CLD)
			Apnea
	Gastrointestinal system (GI)	Feeding intolerance	
		Necrotising enterocolitis (NEC)	
		Gastroesophageal reflux (GER)	

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	Skin		
	Infections and immune system	Pneumonia	
		Sepsis	
		Meningitis	
		Urinary tract infections	
		Invasive fungal infections	
		Disseminated fungal infections	
	Cardiovascular system	Heart failure	
		Patent ductus arteriosus	
		Hypotension	
		Apnea/bradycardia	
	Hematologic system	Anemia	
	Auditory system and hearing		
	Ophthalmic system and vision		
	Central nervous system		
	Neurodevelopmental complication	Motor impairment	Cerebral palsy (CP)

Appendices

			Coordination and motor planning
		Cognitive impairment	Cognitive test scores and mental retardation
			School problems
		Visual impairment	
		Hearing impairment	
		Behavioural and social-emotional problems	
		Severity of disability	
Interventions	Antenatal interventions	Vitamin A to the mother	
	Intrapartum interventions	Prophylactic corticosteroid therapy in preterm labour	
		Antibiotics for PROM/PPROM	
		Antibiotics for preterm labour with intact membranes	
		Delayed cord clamping	
	Postnatal interventions	Neonatal resuscitation	
		Vitamin A supplementation	
		Vitamin K supplementation	

Appendices

		Zinc supplementation	
		Selenium supplementation	
		Chlorhexidine treatment on the cord	
		Case management of neonatal sepsis and pneumonia	
		Kangaroo mother care (KMC)	
		Early breastfeeding	
		Thermal care	
		Application of continued distending pressure or CPAP to the lungs for RDS	
		Intravenous immune globulin (IVIG)	
		Surfactant therapy for RDS	
		Emollient therapy	
		Hand washing	
		Prophylaxis of eye infection	

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		Use of Appropriate Low-cost Technology (incubators, techniques for minimally invasive intravenous access, protection against the excessive use of oxygen)	

Appendices

**K. The heat map analysis of top 40 priorities of different groups
(voting outcomes)**

Rank	Overall(n=507)*	Service users (n=231)	Both (n=55)	HCPs (n=216)
1	1.General prevention	1.General prevention	1.General prevention	1.General prevention
2	17. Stress and physical	2. Prevention of subsequent	17. Stress and physical	24. Cervical cerclage
3	5. Prevention of pre-ecl	17. Stress and physical w	5. Prevention of pre-ecl	67. Prevention of NEC?
4	2. Prevention of subsequ	96. Care package at disch	7. Screening in the first t	5. Prevention of pre-eclam
5	96. Care package at disc	5. Prevention of pre-eclan	2. Prevention of subsequ	14. Twin and triplet pregna
6	7. Screening in the first	83. Infection in infants	96. Care package at disc	9. Allocate service provisio
7	83. Infection in infants	8. Screening of the placen	51. Breastfeeding clinics	10. Transvaginal scanning
8	14. Twin and triplet preg	75. Pain perception	76. Rooming the infants	54. Optimum milk feeding r
9	67. Prevention of NEC?	7. Screening in the first tri	54. Optimum milk feedin	7. Screening in the first trin
10	11. Antenatal clinics	34. Premature rupture of r	48. Kangaroo mother car	12. Group b streptococcus
11	8. Screening of the place	68. Attachment and bondi	14. Twin and triplet preg	39. Umbilical cord clampir
12	54. Optimum milk feedin	51. Breastfeeding clinics	11. Antenatal clinics	11. Antenatal clinics
13	12. Group b streptococc	11. Antenatal clinics	83. Infection in infants	36. Expectant management
14	51. Breastfeeding clinic	14. Twin and triplet pregn	8. Screening of the place	83. Infection in infants
15	75. Pain perception	67. Prevention of NEC?	68. Attachment and bond	63. Treatments are most eff
16	34. Premature rupture o	48. Kangaroo mother care	56. Safe time to introduc	2. Prevention of subsequen
17	9. Allocate service provi	70. Environmental issues	6. Pre-eclampsia and hy	17. Stress and physical wo
18	24. Cervical cerclage	69. Emotional and practic	75. Pain perception	56. Safe time to introduce f
19	39. Umbilical cord clam	31. Lifestyle changes	78. An open approach to	20. Antenatal guidance and
20	10. Transvaginal scanni	20. Antenatal guidance ar	70. Environmental issue	37. Caesarean section for l
21	48. Kangaroo mother ca	45. Lung damage in preter	9. Allocate service provi	34. Premature rupture of m
22	20. Antenatal guidance	52. Length of orogastric /	12. Group b streptococc	33. Intervention after prem
23	45. Lung damage in pret	12. Group b streptococcus	37. Caesarean section fo	45. Lung damage in pretern
24	68. Attachment and bon	78. An open approach to r	61. Breast milk fortifier	51. Breastfeeding clinics
25	6. Pre-eclampsia and hy	39. Umbilical cord clamp	69. Emotional and pract	38. Antenatal corticosteroi
26	52. Length of orogastric	76. Rooming the infants w	31. Lifestyle changes	6. Pre-eclampsia and hyper
27	63. Treatments are most	54. Optimum milk feeding	24. Cervical cerclage	52. Length of orogastric / n
28	56. Safe time to introduc	6. Pre-eclampsia and hyp	10. Transvaginal scanni	43. Intubation for extreme
29	37. Caesarean section fo	43. Intubation for extreme	34. Premature rupture of	75. Pain perception
30	70. Environmental issue	63. Treatments are most e	45. Lung damage in prete	96. Care package at discha
31	78. An open approach to	9. Allocate service provisio	52. Length of orogastric	8. Screening of the placenta
32	69. Emotional and pract	10. Transvaginal scanning	67. Prevention of NEC?	61. Breast milk fortifier
33	36. Expectant managem	37. Caesarean section for	39. Umbilical cord clam	48. Kangaroo mother care
34	76. Rooming the infants	38. Antenatal corticoster	20. Antenatal guidance a	78. An open approach to nc
35	31. Lifestyle changes	61. Breast milk fortifier	33. Intervention after pr	69. Emotional and practica
36	43. Intubation for extre	24. Cervical cerclage	38. Antenatal corticoste	70. Environmental issues
37	38. Antenatal corticoste	56. Safe time to introduce	43. Intubation for extren	31. Lifestyle changes
38	33. Intervention after pr	33. Intervention after prer	36. Expectant managem	68. Attachment and bondin
39	61. Breast milk fortifier	36. Expectant managemen	63. Treatments are most	76. Rooming the infants wi
40	98. Nutrients	98. Nutrients	98. Nutrients	98. Nutrients

*5 participants did not answer to the 'type of respondents'