Name

Study number

Baby OSCAR

Outcome after selective early closure of PDA

Your child's health and development at 2 years

No one knows your child like you do. That is why we would like you to tell us how your child is getting on now they are 2 years of age.

The questions in this booklet ask about your child's health and development and about any extra care your child has had since being discharged home from the neonatal unit. All of this information is very important for the study.

The information you provide will be treated in the strictest confidence and will not be shown to anyone outside the study. For more information on how we process and protect your data, please see our privacy notice available at www.npeu.ox.ac.uk/ctu

If you would like to complete this questionnaire online, your personal access code can be found in the letter we sent with this questionnaire.

If you need any help completing the questionnaire, or have any questions, please do not hesitate to contact the Co-ordinating Centre on 01865 617 965.

Name of person completing this form *(Print)*:

Relationship to child *(Print)*:

Date form completed: ☐☐ / ☐☐ / ☐☐ (Day / Month / Year)

NPEU Clinical Trials Unit

UNIVERSITY OF OXFORD

Section A: Your child's health and physical development

The following questions ask about your child's health and physical development. **Please answer all of the questions as best you can.** You may feel that some of these questions do not apply to your child, but it is important to answer all of them so we can find out about your child's general health and development.

1. In general, how is your child's health compared with other children of the same age?
(please tick one)

- ☐ Excellent
- ☐ Good
- ☐ Fair
- ☐ Poor
- ☐ Not sure

2. Does your child have any difficulties with his or her vision?
(please tick one)

- ☐ No difficulties
- ☐ Needs to wear glasses, but sees well when wearing them
- ☐ Has difficulty seeing, even when wearing glasses
- ☐ Is blind in one eye but has good vision in the other eye
- ☐ Is able to see light only or is blind

3. Does your child have any difficulties with his or her hearing?
(please tick one, but if they intermittently suffer from glue ear please report what their hearing is like when this is less problematic)

- ☐ No difficulties
- ☐ Has some difficulty hearing, but does not need a hearing aid or cochlear implant*
- ☐ Has a cochlear implant or hearing aid, but hears well with it
- ☐ Has difficulty hearing, even with a cochlear implant or hearing aid
- ☐ My child is deaf

**A cochlear implant is a type of electronic hearing aid that has two parts, one that is worn on the ear and one that is implanted inside the ear during an operation*

4. Is your child able to sit *on the floor* on his or her own, without any support?
(please tick one)

- ☐ No difficulties sitting alone
- ☐ Can sit alone but is unstable (may need to use his or her hands for support)
- ☐ Can only sit with support or with help from an adult
- ☐ Unable to sit

5. Is your child able to walk on his or her own, without any support?
(please tick one)

No difficulties walking alone ☐
Can walk a few steps without any help ☐
Can only walk if helped by an adult or a walking aid ☐
Unable to walk, even with help ☐

6. Was your child discharged home on oxygen using a nasal cannula? Yes ☐ No ☐

A nasal cannula is a tube with one end having two prongs that are placed in the nostrils of the baby to deliver oxygen or a mixture of air and oxygen

If Yes – what date did they stop receiving oxygen at home? ☐☐ / ☐☐ / ☐☐
Day / Month / Year

Still on oxygen ☐

If No – has your child received oxygen using a nasal cannula at any time since they were discharged home? Yes ☐ No ☐

7. Since first discharge home from hospital, has your child received any other breathing support?

Yes ☐ No ☐

If Yes, what type of breathing support was it? *(please tick one)*

Ventilator ☐
CPAP ☐
Tracheostomy ☐
Other ☐

If other, please tell us what: _____

8. Since first discharge home from hospital, has your child suffered from a persistent wheeze?

Yes ☐ No ☐

A wheeze is defined as a whistling, squeaky noise coming from the chest when breathing out. Noisy snoring or gurgling, crackling or rattling with a blocked nose or lots of mucus is not wheezing.

Persistent is defined as affecting sleep, exercise (such as playing or running), laughing or crying.

9. Since first discharge home from hospital, has your child suffered from a persistent cough?

Yes ☐ No ☐

Persistent is defined as affecting sleep, exercise (such as playing or running), laughing or crying.

If Yes, does it affect your child's: *(please tick all that apply)*

feeding? ☐
sleep? ☐
physical activity? ☐

10. Since first discharge home from hospital, has your child received treatment for respiratory illness? (e.g. chest infection, wheeze, cough, rattling chest, shortness of breath)

Yes ☐ No ☐

If Yes, which of the following did they need? *(please tick all that apply)*

Inhaler – Relievers, e.g. Ventolin or Bricanyl (blue) ☐

Inhaler – Preventers, e.g. Pulmicort (brown), or Flixotide (yellow) ☐

Steriods, e.g. Prednisolone ☐

Other ☐

If other, please tell us the name(s) of the other medication(s) _____

11. Since first discharge home from hospital, have you taken your child to a GP or Accident & Emergency department for any respiratory illness?

(You will be asked for more details in Section D)

Yes ☐ No ☐

If Yes, how many times? 1–3 ☐

4–12 ☐

More than 12 ☐

12. Since first discharge home from hospital, has your child been admitted to hospital for any respiratory illness?

(You will be asked for more details in Section D)

Yes ☐ No ☐

If Yes, how many times? 1–2 ☐

3–5 ☐

More than 5 ☐

The following questions ask about family health or home circumstances that might affect children's breathing. We would appreciate it if you could answer these questions to help us understand why some children in the study might have breathing difficulties at this age.

13. Is there a history of inhaler prescription for asthma or wheezing in the family? (i.e. parents or siblings) *Please tick all that apply*

Yes ☐ No ☐

Mum ☐

Dad ☐

Siblings ☐

14. Since first discharge home, is there any history of smoking in the home, by a household member or visitor?

Yes ☐ No ☐

15. Since first discharge home, have there been any problems with dust, damp or mould, or have you had any major building work or renovations in the home?

Yes ☐ No ☐

16. Do you live near a busy main road?

Yes ☐ No ☐

Section B: Your child's play

We are interested in finding out about your child's play, as this will give us an idea of how his or her problem-solving skills are developing. Please tell us whether or not your child can do each of the play activities below. If you have seen your child do the activity (or something similar), then tick the box under "Yes". If you know that your child would not be able to do it, then tick the box under "No". If you are not sure, then tick the box for "Don't know." If you don't know, you may like to try out some of the activities with your child.

Please answer all of the questions as best you can.

Please remember that all children develop differently and there are large differences in what children can do at this age. Some of these activities may be easy for your child and others may be difficult. The activities listed are for children up to 4 years of age, so 2 year old children may not be able to do all of them yet.

	Yes	No	Don't Know
1. Does your child copy things you do such as cuddling a teddy? (Try it out if you are not sure by cuddling a teddy and then giving it to your child. Say: Now you cuddle teddy)	☐	☐	☐
2. When you hide a toy in full view of your child, will s/he look for it and find it? (Try this out by covering a small toy with a cloth or a cup and seeing if s/he uncovers it)	☐	☐	☐
3. Can your child put a simple piece, such as a square or an animal, into the correct place in a puzzle board?	☐	☐	☐
4. Some toys have several holes or openings with different shapes, such as a circle, triangle, and star. Could your child put the shapes into the right openings?	☐	☐	☐
5. Can your child stack two small blocks or toys on top of each other?	☐	☐	☐
6. Can your child put together, by him/herself, a puzzle or something similar where the pieces fit together?	☐	☐	☐
6a. If so, can s/he do this for a puzzle with ten or more pieces?	☐	☐	☐
7. Can your child mark on a piece of paper using the tip of a crayon, pencil, or chalk?	☐	☐	☐
8. Can your child draw a more or less straight line on paper?	☐	☐	☐
9. Does your child turn, or try to turn, the pages of a book one at a time?	☐	☐	☐
10. Does your child ever pretend that one object, such as a block, is another object, such as a car or a telephone?	☐	☐	☐
11. Can your child stack three small blocks or toys on top of each other by him/herself?	☐	☐	☐
12. Does your child ever pretend to do things? For example, riding a horse or making a cup of tea?	☐	☐	☐
13. Can your child push a car along the floor with the wheels on the floor?	☐	☐	☐
14. Does your child look with interest at pictures in a book?	☐	☐	☐

	Yes	No	Don't Know
15. Does your child point to pictures in a book?	☐	☐	☐
16. Does your child try to copy things you do, such as stirring with spoon in a cup?	☐	☐	☐
17. Can your child stack seven small blocks or toys on top of each other by him/herself?	☐	☐	☐
18. Does your child point or show where people or objects are when you ask. For example, "Where is the light?", "Where is Daddy?" or "Where is Teddy?"	☐	☐	☐
19. Does your child ever pretend that two dolls are playing together, or are talking to each other, or one is feeding the other?	☐	☐	☐
20. Does your child ever play pretend games with another child, pretending to be someone else, such as a mummy, daddy, policeman, or nurse?	☐	☐	☐
21. Does your child ever play any game with another child that involves taking turns?	☐	☐	☐
22. Does your child ever copy some action shortly (within a few minutes) after s/he has seen it?	☐	☐	☐
23. Can your child fetch something, such as a toy, from another room by him/herself when you ask?	☐	☐	☐
24. Does your child know where some things belong, such as, that his/her toys belong in a box?	☐	☐	☐
25. Does your child ever save or put to one side a biscuit (or snack) for later, on his/her own?	☐	☐	☐
26. Have you ever seen your child get together 3 or more toys before beginning to play with them?	☐	☐	☐
27. Have you ever seen your child sort things (blocks, other toys) into groups or piles that go together on his/her own?	☐	☐	☐
28. If your child wants something out of reach, does s/he go and find a chair or box to stand on?	☐	☐	☐
29. When your child uses or plays with a telephone, does s/he speak into the mouthpiece not the earpiece?	☐	☐	☐
30. When your child drinks from a cup, is s/he careful about putting it down, trying not to spill it?	☐	☐	☐
31. Does your child try to turn doorknobs, twist tops, or screw lids on or off jars?	☐	☐	☐
32. Does your child recognise him/herself when looking in the mirror?	☐	☐	☐
33. Does your child ever use his or her index (first) finger to point to show an interest in something?	☐	☐	☐

Section C: What your child can say

We would also like to know how your child's language is developing. Although children are able to understand many more words than they can say, here we are interested only in the words your child says.

Does your child say any words yet?

Yes ☐ – please answer the rest of the questions in this section

No ☐ – please go straight to Section D, on page 9

As your child has started to use words, please go through the list below and tick all the words you have heard your child say. If your child uses a different pronunciation of a word, e.g., "tend" for pretend, or "duce" for juice – please tick it anyway.

Please remember that children's language develops at very different speeds, and there are large differences in what children can say at this age. Some two year olds may only say one or two words yet, whilst others may say more. Some children might also say other words that are not listed, but for this study we want to know if your child can say any of the words shown below.

☐ Baa baa	☐ Cream cracker	☐ Bed	☐ Carry	☐ Last
☐ Meow	☐ Juice	☐ Bedroom	☐ Chase	☐ Tiny
☐ Ouch/ow	☐ Meat	☐ Settee/sofa	☐ Pour	☐ Wet
☐ Uh-oh/oh dear	☐ Milk	☐ Oven/cooker	☐ Finish	☐ After
☐ Woof woof	☐ Peas	☐ Stairs	☐ Fit	☐ Day
☐ Bear	☐ Hat	☐ Flag	☐ Hug/cuddle	☐ Tonight
☐ Bird	☐ Necklace	☐ Rain	☐ Listen	☐ Our
☐ Cat	☐ Shoe	☐ Star	☐ Like	☐ Them
☐ Dog	☐ Sock	☐ Swing	☐ Pretend	☐ This
☐ Duck	☐ Chin	☐ School	☐ Rip/tear	☐ Us
☐ Horse	☐ Ear	☐ Sky	☐ Shake	☐ Where
☐ Aeroplane	☐ Hand	☐ Zoo	☐ Taste	☐ Beside
☐ Boat	☐ Leg	☐ Friend	☐ Gentle	☐ Down
☐ Car	☐ Pillow	☐ Mummy/mum	☐ Think	☐ Under
☐ Ball	☐ Comb	☐ Person	☐ Wish	☐ All
☐ Book	☐ Lamp/torch	☐ Bye/byebye	☐ All gone	☐ Much
☐ Game	☐ Plate	☐ Hi/hello	☐ Cold	☐ Could
☐ Sandwich	☐ Rubbish	☐ No	☐ Fast	☐ Need to
☐ Fish	☐ Tray	☐ Shopping	☐ Happy	☐ Would
☐ Sauce	☐ Towel	☐ Thank you	☐ Hot	☐ If

We would also like to know how your child uses the words she or he can say. Please look at the next 6 questions and answer them all by ticking one box for each question. Again, please bear in mind that every child develops differently and there are large differences in children's language development at this age. Whilst some children are able to say the words below, other children may not yet be using words so often.

	Not yet	Sometimes	Often
1. Does your child ever talk about past events or people who are not present? For example, a child who saw a carnival last week might later say 'carnival', 'clown', or 'band'.	☐	☐	☐
2. Does your child ever talk about something that is going to happen in the future? E.g. say 'choo-choo' or 'bus' before you leave the house on a trip, or say 'swing' when you are going to the park?	☐	☐	☐
3. Does your child ever talk about objects that are not present? For example, asking about a missing toy not in the room, or asking about someone not present?	☐	☐	☐
4. Does your child understand if you ask for something that is not in the room? For example, would s/he go to the bedroom to get a teddy bear when you say 'Where's the bear?'	☐	☐	☐
5. Does your child know who things belong to? For example, a child might point to mummy's shoe and say 'Mummy'.	☐	☐	☐
6. Has your child started to put together words yet, such as 'Daddy gone' or 'Doggie bite'?	☐	☐	☐

If you answered "Not Yet" to Question 6, please go straight to the next page.

If you answered "Sometimes" or "Often" to Question 6, please answer questions 7–18 below.

For EACH PAIR of sentences below – A and B – please tick the one that sounds MOST like the way your child talks at the moment, even if s/he would not say that EXACT sentence. If your child is saying sentences even more complicated than the two examples provided, please tick B.

7. (Talking about something happening now) A ☐ I make tower B ☐ I making tower	8. (Talking about something that already happened) A ☐ Daddy pick me up B ☐ Daddy picked me up	9. A ☐ That my truck B ☐ That's my truck
10. A ☐ Baby crying B ☐ Baby is crying	11. A ☐ There a doggie B ☐ There's a doggie	12. A ☐ Coffee hot B ☐ That coffee hot
13. A ☐ I no do it B ☐ I can't do it	14. A ☐ I like read stories B ☐ I like to read stories	15. A ☐ Biscuit Mummy B ☐ Biscuit for Mummy
16. A ☐ Don't read book B ☐ Don't want you read that book	17. A ☐ Baby want eat B ☐ Baby want to eat	18. A ☐ Look at me B ☐ Look at me dancing

Section D: Hospital/Community Services

The following section asks about your child's use of hospital/community services since being first discharged home from the hospital. *Please answer all of the questions as accurately as possible. If you run out of space, please use the extra space on page 11.*

1. Since your child was first discharged home from the hospital, did they have an operation to close a PDA?

Yes ☐ No ☐

If Yes, please give date of operation. ☐☐ / ☐☐ / ☐☐ (Day / Month / Year) ***or*** Age ☐ *years* ☐☐ *months*

2. Since your child was first discharged home from the hospital, has your child been admitted to hospital? *(Please include any admissions already mentioned in Section A Question 12)*

Yes ☐ No ☐

If Yes, please provide details for each admission.

Date admitted	Reason for hospital admission (e.g. breathing problems)	Was this a planned admission?	Did your child stay overnight?	Did your child receive intensive care?	Did your child have an operation?
Month / Year		**Yes / No**	**Yes / No**	**Yes / No**	**Yes / No**
☐☐ / ☐☐☐☐ (Month / Year)	☐	Y ☐ N ☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, what was the operation type? ________
☐☐ / ☐☐☐☐ (Month / Year)	☐	Y ☐ N ☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, what was the operation type? ________
☐☐ / ☐☐☐☐ (Month / Year)	☐	Y ☐ N ☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, what was the operation type? ________
☐☐ / ☐☐☐☐ (Month / Year)	☐	Y ☐ N ☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, what was the operation type? ________
☐☐ / ☐☐☐☐ (Month / Year)	☐	Y ☐ N ☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, what was the operation type? ________
☐☐ / ☐☐☐☐ (Month / Year)	☐	Y ☐ N ☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, for how many nights? ☐☐☐	Y ☐ N ☐ If Yes, what was the operation type? ________

3. **Since your child was first discharged home from the hospital, has your child attended a hospital outpatient department/clinic?** *(Please include any attendances already mentioned in Section A Question 11)*

Yes ☐ No ☐

If Yes, please provide details for each individual visit.

Type of clinic	Attended? *(please tick)*	Number of times	Reason
Accident and Emergency *(and not admitted)*	Yes ☐	☐☐	
Audiology / Hearing	Yes ☐	☐☐	
Eye / Vision	Yes ☐	☐☐	
General Medical	Yes ☐	☐☐	
Paediatric / Neonatal follow-up clinic	Yes ☐	☐☐	
Other *(please specify)* ☐	Yes ☐	☐☐	
Other *(please specify)* ☐	Yes ☐	☐☐	
Other *(please specify)* ☐	Yes ☐	☐☐	

4. **Has your child seen any of the following community professionals since their first discharge home from the hospital?** *(please indicate YES or NO for all)*

Community Professional		Total number of visits
Community nurse	Yes ☐ No ☐	☐☐☐
Community paediatrician	Yes ☐ No ☐	☐☐☐
Dietician	Yes ☐ No ☐	☐☐☐
Physiotherapist	Yes ☐ No ☐	☐☐☐
Speech and language therapist	Yes ☐ No ☐	☐☐☐
Other *(please specify)* _____	Yes ☐ No ☐	☐☐☐

Section E: Additional/other information

Is there anything else you would like to tell us about your child's health and development? If so, please write it in this box.

Thank you for completing this questionnaire.

Your contribution to the Baby-OSCAR study is greatly appreciated.

Please return the questionnaire to:

Freepost RLSL-SBZK-HTAT
Baby-OSCAR Co-ordinating Centre, NPEU Clinical Trials Unit,
University of Oxford, Old Road, Headington, Oxford, OX3 7LF

If you have any questions, please contact the Baby-OSCAR Co-ordinating Centre on 01865 617 965

We will send you a summary of the results at the end of the study. In the meantime, if you have any questions, please do not hesitate to contact the Baby-OSCAR Co-ordinating Centre.

If you have any concerns about your child's health or development, please contact your child's GP or health visitor. Children in the UK are routinely offered an assessment by a health visitor when they are around 2½ years of age, so you may be due to see your health visitor soon. You can find out more about how to contact your health visitor in your child's red book.

Advice or support with issues related to parenting children born prematurely can be sought from Bliss, the UK charity for babies born too soon, too small, too sick.

You can contact them at:

Bliss
for babies born premature or sick

020 7378 1122
www.bliss.org.uk

Bliss Head Office, 2nd Floor, Chapter House, 18-20 Crucifix Lane,
London SE1 3JW

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Sections B–C based on the PARCA-R

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