

NEONATAL CARE EXPERIENCE SURVEY

This survey is about your experiences with NHS neonatal care.

Neonatal care is for babies who are born early or who are unwell. Your answers will help the NHS understand what you think about neonatal care – and how it can be made better.

What to do

To take part in the survey, please fill in this questionnaire and send it back in the **FREEPOST** envelope provided. The questionnaire asks about the mother’s recent experience of neonatal care and has some questions for the other parent at the end. If it is not relevant or the other parent is not able to complete it, then please skip this section. The questionnaire should take less than 20 minutes to complete.

Use a black or blue pen and put a clear cross inside one box for each question. Some questions let you choose more than one box – it will say if you can. Some boxes will tell you to skip to a different question. Please follow these instructions carefully so that you only answer the questions that are relevant to you.

Don’t worry if you make a mistake; simply fill in the wrong box and put a cross in the correct box. If you can’t answer a question, or don’t want to answer, leave it blank and go on to the next question. If you would like help filling in the survey, a friend or family member can help you, or you can call the helpline number below. Please make sure that the answers are about your own experiences, except for Section I, which is for the baby’s other parent. Taking part is your choice. **Your answers will be treated in confidence.**

If you have any questions about the survey:

Call our Freephone helpline on **0800 103 2805** between 10am and 4pm, Monday to Saturday.

Email us at neonatal.survey@pickereurope.ac.uk

If you had twins, triplets, or more than one baby that was admitted to neonatal care in different units please answer about the baby/babies cared for in the hospital named on the covering letter.

SECTION A: INVOLVEMENT IN YOUR BABY’S CARE

Please answer the following questions about the neonatal unit at the hospital named on the covering letter to this questionnaire.

A1 Were you supported by neonatal staff to touch or comfort your baby?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

A2 During the first few days, were you supported by neonatal staff to have skin-to-skin contact with your baby?

- 1 Yes
- 2 No
- 3 This was not possible for medical reasons

A3 Were you able to plan your baby’s activities (like weighing or bathing) at times when you could be on the neonatal unit?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, never
- 4 Don’t know / can’t remember

A4 Did neonatal staff support you to feel confident in caring for your baby?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No

- A5** Were you told about any changes in your baby's condition or care by neonatal staff?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, I was not told about any changes
 - 4 Don't know / can't remember

- A6** Were your wishes respected by neonatal staff about how you wanted to feed your baby?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, never
 - 4 Don't know / can't remember

- A7** Did neonatal staff give you the support you needed to feed your baby?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember

SECTION B: STAFF ON THE NEONATAL UNIT

Still thinking about the hospital named on the covering letter...

- B1** When you asked neonatal staff questions, did you get answers you could understand?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, never
 - 4 I did not have any questions
 - 5 I did not feel able to ask questions
 - 6 Don't know / can't remember

- B2** Did you have confidence and trust in the neonatal staff looking after your baby?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, never

- B3** Did you feel your baby was treated with respect and dignity by staff whilst on the neonatal unit?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, never

- B4** Were you treated with kindness and compassion by neonatal staff?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, never

- B5** Were your cultural or religious needs respected by neonatal staff during your baby's stay on the neonatal unit?
- 1 Yes, completely
 - 2 Yes, to some extent
 - 3 No
 - 4 I did not have any specific needs

- B6** Did you feel that you could raise any worries or concerns to neonatal staff on the unit, if you had any?
- 1 Yes, always **Go to B7**
 - 2 Yes, sometimes **Go to B7**
 - 3 No, never **Go to B7**
 - 4 I had no worries or concerns **Go to B8**

- B7** If you raised worries or concerns to members of neonatal staff, did you feel they were taken seriously?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, never
 - 4 I had no worries or concerns
 - 5 Don't know / can't remember

- B8** A range of professionals may be involved in supporting you and your baby during their time on the neonatal unit. Did you receive support from any of the following?

Please cross X in all the boxes that apply

- 1 Dietician
- 2 Occupational therapist
- 3 Hospital Pharmacist
- 4 Physiotherapist
- 5 Speech and Language Therapist
- 6 None of the above
- 7 Don't know / can't remember

SECTION C: ENVIRONMENT AND FACILITIES

Still thinking about the hospital named on the covering letter...

- C1** Was the purpose of any machines, monitors and alarms your baby needed on the neonatal unit explained to you in a way you could understand?
- 1 Yes, definitely
 - 2 Yes, to some extent
 - 3 No
 - 4 Don't know / can't remember

- C2** Were you given enough privacy when discussing your baby's care on the neonatal unit with staff?
- 1 Yes
 - 2 No
 - 3 No, but I did not mind

- C3** Was there a comfortable place for you to sit alongside your baby on the neonatal unit?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, never

- C4** Were neonatal staff supportive of you being able to be with your baby on the neonatal unit any time you wanted?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, never
 - 4 Don't know / can't remember

- C5** Were you able to independently access the neonatal unit without staff letting you in (e.g. digital access, fingerprint, swipe card)?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, never

- C6** If you wanted to stay overnight to be close to your baby, did the neonatal unit provide a bed for you to sleep in?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, never
 - 4 I did not want / need to stay overnight

SECTION D: INFORMATION AND SUPPORT FOR YOU

Still thinking about the hospital named on the covering letter...

- D1** Did the information you received when on the neonatal unit help you understand your baby's condition and treatment?
This includes any verbal, written or online information.
- 1 Yes, definitely **Go to D2**
 - 2 Yes, to some extent **Go to D2**
 - 3 No **Go to D2**
 - 4 I did not receive any information **Go to D4**

- D2** Did you feel that the information you received when on the neonatal unit was consistent?
- 1 Yes, always
 - 2 Yes, sometimes
 - 3 No, never
 - 4 Don't know / can't remember

D3 How helpful was the information you received when on the neonatal unit about your baby's condition or treatment?

- 1 Very helpful
- 2 Somewhat helpful
- 3 Not very helpful
- 4 Not at all helpful

D4 If you had other caring responsibilities, did neonatal staff take these into account when helping you care for your baby?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I had no other caring responsibilities

D5 Did you feel emotionally supported by staff on the neonatal unit?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 No, but I did not need this

D6 Was specialist psychological support offered to you during your time on the neonatal unit (from a trained psychological professional)?

- 1 Yes
- 2 No
- 3 No, but I did not need this

D7 Were you given information about help you could get with expenses related to your baby's stay on the neonatal unit (such as travel / parking expenses, hardship funds or food)?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know / can't remember

D8 Did financial pressures during your baby's stay on the neonatal unit ever limit the amount of time you were able to spend with them?

- 1 Yes, a lot
- 2 Yes, a little
- 3 No, not at all

SECTION E: BEING TRANSFERRED TO ANOTHER HOSPITAL

E1 Was your baby ever transferred between neonatal units at different hospitals?

- 1 Yes **Go to E2**
- 2 No **Go to F1**

E2 Were you told in advance that your baby was going to be transferred to a different hospital?

- 1 Yes
- 2 No
- 3 No, but the transfer was an emergency

E3 Did neonatal staff explain why your baby was being transferred to a different hospital in a way you could understand?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No

E4 Were you given information when you needed it about the hospital where your baby was being transferred to (such as location and facilities)?

- 1 Yes
- 2 No

E5 Were neonatal staff on the new unit aware of the care your baby had received so far?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 Don't know / can't remember

SECTION F: DISCHARGE FROM THE NEONATAL UNIT

Thinking about the hospital named on the covering letter...

F1 Before discharge, were the medicines you were given for your baby explained to you in a way that you could understand?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 My baby did not need medicine

F2 Were you given information by neonatal staff in a way you could understand about your baby's longer-term development, progress and ongoing healthcare needs?

- 1 Yes, completely
- 2 Yes, to some extent
- 3 No
- 4 I did not want / need this

F3 After your baby arrived home, did you have support from **neonatal staff**?

Please cross X in all the boxes that apply

- 1 Yes, by telephone
- 2 Yes, staff from the unit visited me at home
- 3 Yes, my baby had a follow up hospital appointment
- 4 No, but I would have liked support from neonatal staff
- 5 No, I did not want / need support from neonatal staff

F4 If you saw a **health visitor at home**, did they know enough about your baby's medical history?

- 1 Yes, definitely
- 2 Yes, to some extent
- 3 No
- 4 I did not see a health visitor

SECTION G: OVERALL ON THE NEONATAL UNIT

G1 How long overall did your baby stay in **neonatal care** (include all the hospitals they stayed in)?

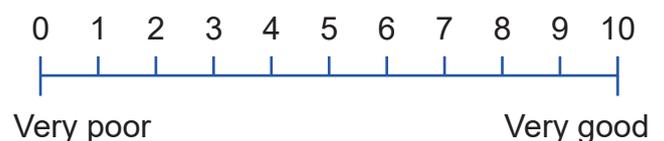
- 1 Less than 1 week
- 2 1 week to less than 4 weeks
- 3 4 weeks to less than 8 weeks
- 4 8 weeks to less than 12 weeks
- 5 12 weeks or more

Thinking about the hospital named on the covering letter...

G2 Did you feel you were treated with respect and dignity by neonatal staff whilst your baby was on the neonatal unit?

- 1 Yes, always
- 2 Yes, sometimes
- 3 No, never

G3 Overall, how was the experience of the care your baby received while on the neonatal unit? **Please give your answer on a scale of 0 to 10, where 0 means a very poor experience and 10 means a very good experience.**



G4 Was your baby mainly cared for on the neonatal unit at the hospital named in the covering letter?

- 1 Yes
- 2 No

SECTION H: ABOUT YOU

Please complete as many of these questions as you can. Your answers will help us to anonymously describe those taking part in the survey and to find out whether neonatal care is the same regardless of people's background or circumstances.

H1 Have you previously had a baby admitted to a neonatal unit?

- 1 Yes
- 2 No
- 3 I would prefer not to say

H2 Is English your main language?

- 1 Yes
- 2 No
- 3 I would prefer not to say

H3 What year were **you** born?

Please write in e.g.

1	9	9	4
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H4 Do you have any physical or mental health conditions, disabilities or illnesses that have lasted or are expected to last 12 months or more?

- 1 Yes **Go to H5**
- 2 No **Go to H6**
- 3 I would prefer not to say **Go to H6**

H5 Do any of these conditions reduce your ability to carry out day-to-day activities?

- 1 Yes, a lot
- 2 Yes, a little
- 3 No, not at all
- 4 I would prefer not to say

H6 What is your religion?

- 1 No religion
- 2 Buddhist
- 3 Christian (including Church of England, Catholic, Protestant, and other Christian denominations)
- 4 Hindu
- 5 Jewish
- 6 Muslim
- 7 Sikh
- 8 Other
- 9 I would prefer not to say

H7 Which of the following options best describes how you think of yourself?

- 1 Heterosexual / straight
- 2 Gay / lesbian
- 3 Bisexual
- 4 Other
- 5 I would prefer not to say

H8 During your baby's stay on the neonatal unit, did you feel you were treated unfairly or discriminated against by staff?

- 1 Yes, definitely **Go to H9**
- 2 Yes, to some extent **Go to H9**
- 3 No **Go to H10**
- 4 I would prefer not to say **Go to H10**

H9 What do you think or feel this was related to? **Please cross X in all the boxes that apply**

- 1 Age
- 2 Disability
- 3 Gender reassignment
- 4 Marriage or civil partnership
- 5 Pregnancy or maternity
- 6 Race
- 7 Religion or belief
- 8 Sex
- 9 Sexual orientation

H10

What is your ethnic group?

Please cross X in ONE box only

a. WHITE

- 1 English / Welsh / Scottish / Northern Irish / British
- 2 Irish
- 3 Gypsy or Irish Traveller
- 4 Roma
- 5 Any other White background, **please write in**

b. MIXED / MULTIPLE ETHNIC GROUPS

- 6 White and Black Caribbean
- 7 White and Black African
- 8 White and Asian
- 9 Any other Mixed / multiple ethnic background, **please write in**

c. ASIAN / ASIAN BRITISH

- 10 Indian
- 11 Pakistani
- 12 Bangladeshi
- 13 Chinese
- 14 Any other Asian background, **please write in**

d. BLACK / AFRICAN / CARIBBEAN / BLACK BRITISH

- 15 African
- 16 Caribbean
- 17 Any other Black / African / Caribbean background, **please write in**

e. OTHER ETHNIC GROUP

- 18 Arab
- 19 Any other ethnic group, **please write in**

- 20 I would prefer not to say

YOUR COMMENTS

If there is anything else you would like to tell us about the neonatal care received in the hospital named in the letter sent with the questionnaire, then please do so here.

The comments you provide in the box below will be shared with and looked at in full by NHS organisations and networks to help improve the quality of care for babies and families. Any information you give that could identify anyone will be shared with these organisations. NHS England will remove any information that could identify you before it publishes findings based on any of your feedback.

THANK YOU VERY MUCH FOR YOUR HELP

There is an optional section on the back of this questionnaire for the baby's other parent to complete. Not all families will use this section.

You can return the questionnaire **with or without** this section completed using the **FREEPOST** envelope provided.
No stamp is needed.

SECTION I: THE BABY'S OTHER PARENT

This section includes questions for the baby's other parent who was on the neonatal unit to understand their experiences of neonatal care. Taking part in this survey is voluntary. If this is not relevant to you or your family, please skip these questions and return the questionnaire in the **FREEPOST** envelope provided.

Your answers will be combined with others answering this section and NHS England will publish the anonymous results on the Neonatal Care Experience Survey website: nhsneonatalsurvey.co.uk

If the main respondent (mother) later withdraws from the survey ahead of data processing, any anonymous feedback you've provided in this section will also be excluded. You can withdraw your response to this section by contacting:

0800 103 2805 or

neonatal.survey@pickereurope.ac.uk and quoting the reference code from the covering letter.

Thinking about the hospital named on the covering letter...

11 Were you supported by neonatal staff to touch or comfort your baby?

- 1 Yes, definitely
2 Yes, to some extent
3 No

12 Were you able to plan your baby's activities (like weighing or bathing) at times when you could be on the neonatal unit?

- 1 Yes, always
2 Yes, sometimes
3 No, never
4 Don't know / can't remember

13 Did neonatal staff support you to feel confident in caring for your baby?

- 1 Yes, definitely
2 Yes, to some extent
3 No

14 Did neonatal staff make you feel that **you** were an important part of your baby's care?

- 1 Yes, definitely
2 Yes, to some extent
3 No

15 If you wanted to stay overnight to be close to your baby, did the neonatal unit provide a bed for you to sleep in?

- 1 Yes, always
2 Yes, sometimes
3 No, never
4 I did not want / need to stay overnight

16 Did you feel emotionally supported by staff on the neonatal unit?

- 1 Yes, definitely
2 Yes, to some extent
3 No
4 No, but I did not need this

YOUR COMMENTS

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