

PINSA:

Providing Information about Newborn Screening Antenatally

Introduction

My name is _____ and I am a researcher from the University of Manchester.

The main aim of this survey is to understand the way in which information about the Newborn Blood Spot Screening Programme is currently provided to parents.

The second aim of this survey is to discover if there are any barriers to the provision of information by health professionals.

It is important that your answers represent what you actually do in practice rather than what guidelines advise should be done. Your answers will be anonymised.

The survey will take no more than 30 minutes to complete and you will have the opportunity to add any extra comments about Newborn Bloodspot Screening or the survey at the end.

In terms of data collection it would be helpful for me to tape-record the survey - Are you happy for me to tape-record the survey?

Would you like to be entered into a prize draw for the chance to win a £50 Marks and Spencers voucher as a thank you for taking part?

Providing Information Before Birth

The questions in this section ask you about providing information before birth

1. In your NHS role, do you give information about Newborn Blood Spot Screening to parents before birth?

Yes No

(IF NO, PLEASE GO TO QUESTION 8)

2. Which of the following options do you use to provide information about Newborn Blood Spot Screening before birth? I will now read the options available to you. You are allowed to indicate more than one option.

- Face to face discussion with parents
- Screening for you and your baby leaflet
- Blood spot screening for your baby leaflet
- Other (write the response in the box below)

(IF DISCUSSION NOT SELECTED GO TO QUESTION 6)

3. If you discuss Newborn Screening with parents face to face, when in a woman's pregnancy would you generally do this?

(If exact answer provided enter this, if not prompt with options below) I will now read the options available to you. Please choose just one option.

- N/A 11-20 Weeks 31 Weeks-Birth
- Booking 21-30 Weeks

4. If you discuss Newborn Screening with parents face to face, where would you typically do this? I will now read the options available to you. You are allowed to indicate more than one option.

- N/A In Hospital Midwife Led Delivery Unit
- Antenatal Clinic At Parent's Home
- Other (write the response in the box below)

5. If you discuss Newborn Screening with parents face to face, how long on average do you spend doing so?

(If exact answer provided enter this, if not prompt with options below) I will now read the options available to you. Please choose just one option.

- N/A 11-20 Minutes
 0-5 Minutes 21-30 Minutes
 6-10 Minutes Longer than 30 minutes

6. If you provide pregnant women with the Screening for You and Your Baby Leaflet, when in a woman's pregnancy would you generally do this?

(If exact answer provided enter this, if not prompt with options below) I will now read the options available to you. Please choose just one option.

- N/A 11-20 Weeks 31 Weeks-Birth
 Booking 21-30 Weeks

7. If you provide pregnant women with the Screening for You and Your Baby leaflet, where would you typically do this? I will now read the options available to you. You are allowed to indicate more than one option.

- N/A In Hospital Midwife Led Delivery Unit
 Antenatal Clinic At Parent's Home
 Other (please specify)

Information: After Birth but Before the Test

The questions in this section asks you about providing information after the birth but before the test is done

8. Do you provide any information about Newborn Blood Spot Screening after birth but before the screening is carried out?

- Yes No

(IF NO, PLEASE GO TO QUESTION 13)

9. How long after birth but before conducting the screening test do you provide information about Newborn Blood Spot Screening? I will now read the options available to you. You are allowed to indicate more than one option.

- Immediately before test
- 24 hours before test
- Longer than 24 hours before test

10. Where does this information provision generally take place? I will now read the options available to you. You are allowed to indicate more than one option.

- N/A
- In Hospital
- At Parent's Home
- Midwife Led Delivery Unit
- Other (please specify)

11. What form does this information provision take (tick all that apply)? I will now read the options available to you. You are allowed to indicate more than one option.

- Face to face discussion with parents
- Screening for you and your baby leaflet
- Blood spot screening for your baby leaflet
- Other (please specify)

(SKIP QUESTION 12 and go to question 13 IF DISCUSSION NOT TICKED ABOVE)

12. If you discuss screening with parents after birth but before the heel prick test, how long would you typically spend on this topic?

(If exact answer provided enter this, if not prompt with options below) I will now read the options available to you. Please select one option.

- | | |
|---------------------------------------|---|
| <input type="checkbox"/> N/A | <input type="checkbox"/> 11-20 Minutes |
| <input type="checkbox"/> 0-5 Minutes | <input type="checkbox"/> 21-30 Minutes |
| <input type="checkbox"/> 6-10 Minutes | <input type="checkbox"/> Longer than 30 minutes |

Taking Informed Consent for Newborn Blood spot Screening

The questions in this section asks you about taking informed consent for newborn bloodspot screening

13. In your role in the NHS do you personally take informed consent for Newborn Blood Spot Screening?

- Yes No

(IF NO, PLEASE GO TO QUESTION 20)

14. On average, how many parents do you see to take informed consent for Newborn Blood Spot Screening from per week?

(If exact answer provided enter this, if not prompt with options below) I will now read the options available to you. Please select one option.

- | | |
|-------------------------------|---------------------------------------|
| <input type="checkbox"/> 0-2 | <input type="checkbox"/> 11-20 |
| <input type="checkbox"/> 3-5 | <input type="checkbox"/> More than 20 |
| <input type="checkbox"/> 6-10 | |

15. Who do you generally prefer to gain informed consent from?

(If exact answer provided enter this, if not prompt with options below) I will now read the options available to you. Please select one option.

- | | |
|---|-------------------------------------|
| <input type="checkbox"/> Mother only | <input type="checkbox"/> Carer |
| <input type="checkbox"/> Partner only | <input type="checkbox"/> It depends |
| <input type="checkbox"/> Mother and Partner | |

Other (please specify)

16. If you prefer to gain informed consent from a specific person, why is this?

17. How do parents give informed consent for Newborn Blood Spot Screening? (*e.g. verbally or written*)

18. Do you ever use interpreters to provide information and take consent from parents who do not speak English as their first language?

Yes

No

19. If yes, roughly how often would you encounter a set of parents who required an interpreter? (*i.e. once a week, once a month etc*)

Providing Information About Repeat Tests

The next section will ask you about providing information to parents about the need to conduct a repeat test.

A repeat test may be needed if:

- The results were near to being positive and verification is needed.
- The first sample was not collected properly.
- Other problems such as the loss of the sample in the post.

20. If the first sample collection failed and it is necessary to take a second heel prick sample for testing, who usually explains the need for a follow up bloodspot sample collection to the parents? I will now read the options available to you. Please select one option.

- Me
- An explanation is not usually given
- Other (please specify)

(IF NOT ME, PLEASE GO TO QUESTION 21)

21. If you, how long do you spend explaining why it is necessary to collect a second bloodspot sample?

(If exact answer provided enter this, if not prompt with options below) I will now read the options available to you. Please select one option.

- N/A 11-20 Minutes
- 0-5 Minutes 21-30 Minutes
- 6-10 Minutes Longer than 30 minutes

22. On average, how many second blood spot sample collections do you have to conduct in a week?

(If exact answer provided enter this, if not prompt with options below) I will now read the options available to you. Please select one option.

- 0-2 11-20
- 3-5 More than 20
- 6-10

General Questions About Newborn Blood Spot Screening

23. How important do you believe **presenting information** about the Newborn Blood Spot Screening test is relative to your other duties? I will now read the options available to you. Please select one option.

- A lot more important
- More important
- Equally important
- Less important
- A lot less important

24. Please explain your answer to the above question

25. Do you feel that your other duties limit the amount of time you have to present information about Newborn Blood Spot Screening?

- Yes No

26. Please explain your answer to the above question

Some Questions About Yourself

27. What is your role in the NHS? (e.g. Community midwife, hospital based, student etc)

28. What is your pay grade?

- | | |
|---------------------------------|-------------------------------------|
| <input type="checkbox"/> Band 2 | <input type="checkbox"/> Band 6 |
| <input type="checkbox"/> Band 3 | <input type="checkbox"/> Band 7 |
| <input type="checkbox"/> Band 4 | <input type="checkbox"/> Band 8 A-C |
| <input type="checkbox"/> Band 5 | <input type="checkbox"/> Student |

29. What is the name of the NHS trust you work in?

30. Is your trust involved in the pilot for expanded newborn screening?

- Yes No Don't Know

31. Do you have any other comments about providing information about Newborn Blood Spot Screening?

32. Do you have any further comments about this survey?

33. Would you be willing to receive information about taking part in further studies in this project?

Yes

No

(CHECK IF EMAIL ADDRESS GIVEN FOR PRIZE DRAW, IF NOT PLEASE RECORD BELOW)

Thank you for taking the time to complete this survey.

Your responses will help us to discover how information about Newborn Bloodspot Screening is currently given to parents and whether there are any pressures on this.