



your baby's expected or actual date of birth
whether your pregnancy/birth is single or multiple (and if you are having twins or triplets, which
baby/babies you give your consent for)

The study team will store this information securely in their database.

If you decide to take part, a portion from your baby's blood spot card will be collected and sent to the NHS Oxford Regional Genetics Laboratories, and submitted for genetic testing for SMA. The data from this sample will be securely stored for 12 months and any leftover sample will be stored and destroyed after 3 months.

You will be emailed separately to your standard newborn screening results (via the email address you give if you consent to take part in the study) and your baby's screening result. This is normal and means SMA is not suspected. The SMA test result may take longer than your standard newborn screening results. Please ensure you enter a current, personal email address on the consent form, and one that will be monitored regularly for the next 6 months to ensure you receive the results.

If your baby is found to be screened positive for SMA, you will be contacted by phone as soon as possible. You will be invited to a meeting in person with a senior consultant who is an SMA specialist and their clinical team within 2 working days, or as soon as it is practically possible for you. A second test will be done to confirm the diagnosis and here the next steps will be discussed. Any treatment that is required for your baby would be provided through the NHS and is not part of this research study.

95% of people having SMA will be detected by this test- as this test looks for a specific deletion that is present in 95% of affected individuals. In 5% of people with SMA, the *SMN2* gene is mutated and that cannot be found by this screening test. If your child has the rarer mutation, we may not detect it.

In some cases, other personal details including your baby's NHS number will be collected and used by the study team for processing purposes i.e. to match the blood spot card with the consent. The postcode is to ensure that you are not out of the eligible area for the study. If after birth you have moved, it may not be possible to screen your baby for SMA.

Occasionally, due to the way in which your baby's sample might be sent to another laboratory depending on where you receive your post-natal care. This means a different laboratory processes the bloodspot card, and this, unfortunately, means we would not be able to provide you with a result.

The data that we obtain from you and your baby will be kept strictly confidential.

The data protection regulation requires us to tell you how we will process information about you and your baby and what the legal basis for processing is. We will be processing your data for research in the public interest. The University of Oxford is the sponsor for this study, based in the United Kingdom, and is the data controller for the NBS SMA study, therefore they are responsible for making sure all personal information from you and your baby is managed appropriately.

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