







Your involvement

We would like your permission to collect the following **from you**:

| What we would like to collect | Why we collect it | How we collect it | When we collect it |
|--|---|---|--|
|  Saliva (less than 2ml - less than half a teaspoon) | To obtain your DNA* | We will provide a special kit and simple instructions. | You can do this yourself at home and post the sample back to the research team in a freepost envelope. |
|  Questionnaire | Your questionnaire responses will give us important information about your family's background, your health and your environment. | You will receive your questionnaires through the post, and then send them back to the research team in a freepost envelope. | After you have been to your child's 5-year audit clinic. |
|  Further questionnaires | Following your progress over time will help us to understand your child's treatment journey and how you are coping with any difficulties. | You will receive your questionnaires through the post, and then send them back to the research team in a freepost envelope. | At important time points throughout your child's development. |
|  Information from your medical records | This information will tell us more about your past and current health and how this may relate to cleft lip and palate. | We collect it from the relevant departments and organisations. | This is an ongoing process. |

* See Participant Information Sheet for further information about DNA

Your child's involvement

We would like your permission to collect the following **from your child**:

| What we would like to collect | Why we collect it | How we collect it | When we collect it |
|--|--|---|--|
|  Saliva (less than 2ml - less than half a teaspoon) | To obtain their DNA.* | We will provide a special kit and simple instructions. | You can do this yourself at home and post the sample back to the research team in a freepost envelope. |
|  Information from your child's medical records | This information will tell us more about your child's health and how this may relate to cleft lip and palate. | We will access your child's medical records through the relevant departments and organisations. | This is an ongoing process. |
|  Information from your child's educational records | Information about how your child gets on at school may tell us more about the longer-term effects of cleft lip and palate. | We collect it from the Department for Education. | This is an ongoing process from when the child starts school to when they leave compulsory education. |

* See Participant Information Sheet for further information about DNA