

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.	Your cleft team may be able to assist you with this. Otherwise 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 either from your cleft team or through the post, and then send them back to the research team in a freepost envelope.	Around the time of 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 either from your cleft team or 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
 <p>Saliva (less than 2ml - less than half a teaspoon)</p>	To obtain their DNA.*	We will provide a special kit and simple instructions.	Your cleft team may be able to assist you with this. Otherwise you can do this yourself at home and post the sample back to the research team in a freepost envelope.
 <p>Information from your child's medical records</p>	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.
 <p>Information from your child's educational records</p>	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

Your other child(ren)'s involvement

We believe that involving the whole family in this research project will give us much richer information and therefore we would like to collect information from your other child(ren) if applicable. We would like them to take part **whether they were born with a cleft or not.**

We would like your permission to collect the following **from your other child(ren):**

What we would like to collect	Why we collect it	How we collect it	When we collect it
 <p>Saliva (less than 2ml - less than half a teaspoon)</p>	To obtain their DNA*	We will provide a special kit and simple instructions.	Your cleft team may be able to assist you with this. Otherwise you can do this yourself at home and post the sample back to the research team in a freepost envelope.
 <p>Information from your other children's medical records</p>	This information will tell us more about your other children'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.

* See Participant Information Sheet for further information about DNA