





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/hospital staff 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 to complete and send back to the research team in the freepost envelope.	After diagnosis
 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 to complete and send back to the research team in the 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
 Umbilical cord blood	Cord blood is valuable for telling us about the health and environment of your baby whilst in your womb. It also gives us a sample of your baby's DNA and other biological information.*	We take a small amount of blood from the umbilical cord after birth.	After the umbilical cord has been cut and you and your baby have separated from the cord and placenta. This will not hurt your baby.
 Saliva (less than 2ml - less than half a teaspoon)	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.
 Blood (1-2ml - less than half a teaspoon)	To obtain their DNA and other biological information.*	The anaesthetist will take a small sample of blood from your baby.	During your child's surgery.
 Discarded tissue	To obtain their DNA.*	The surgeon takes the tissue during the lip or palate repair operation. It is excess tissue that would usually be discarded and destroyed.	During your child's surgery.
 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