

# The Cleft Collective Birth Cohort Study

## Antenatal diagnosis



**The cleft teams/ hospital staff identify and approach families who have received an antenatal diagnosis of cleft.**

Expected intake of participants (UK wide) = up to 300 families over 3.5 years, using a gradual approach.



Parents receive Starter Pack which includes further information about the research.

Parents sign the Consent Forms for themselves and their other children (if applicable) and return them.



Parents complete questionnaires and return them to the researchers by post.



Baby is born.  
Cord blood is collected at birth (in collaboration with maternity units).



Parents sign the Consent Form for their newborn baby and return it to their cleft team.



Around the time of the lip/palate repair surgery the researchers will collect:

Saliva from parents, Saliva from up to 200 siblings, Saliva from the baby, Blood and tissue from the baby (during surgery).

Biological samples will be sent to the laboratory to be securely stored.



Analysis is carried out anonymously on biological samples and questionnaire data.

The researchers link up to medical and educational records.



Anonymous findings are reported.

Families will be given the opportunity to take part in related cleft studies.

The researchers continue to follow families as the children grow up.