

<p>I understand that my saliva and cord blood samples will be stored in Bristol but these samples and data obtained from them (with anonymous number only) may be sent to specialist research laboratories in the UK and abroad for analyses. Researchers at these laboratories have no access to my personal information.</p>	<input type="checkbox"/> <input type="checkbox"/>
<p>I understand that my anonymous samples and data will only be shared with researchers who are conducting projects approved by a research ethics committee. Researchers have no access to my personal information.</p>	<input type="checkbox"/> <input type="checkbox"/>
Biological samples and Questionnaires	
<p>I agree to The Cleft Collective collecting a saliva sample from me. I agree to my saliva being stored for research, including detailed analysis of my whole genome.</p>	<input type="checkbox"/> <input type="checkbox"/>
<p>I agree to The Cleft Collective collecting a sample of umbilical cord blood following the birth of my child. I agree to my child's umbilical cord blood being stored for research, including detailed analysis of their whole genome.</p>	<input type="checkbox"/> <input type="checkbox"/>
<p>I understand that the information from questionnaires I complete will be used for research purposes only and I cannot be identified from this information.</p>	<input type="checkbox"/> <input type="checkbox"/>
<p>I agree to my data and samples being stored and analysed for future cleft related research that has been ethically approved.</p>	<input type="checkbox"/> <input type="checkbox"/>
Feedback	
<p>I understand that I will not be receiving any feedback unless a specific genetic cause for cleft with relevance to my family has been identified with very high confidence and confirmed by an expert team.</p> <p>If this has been identified in the collected samples I would like to receive feedback.</p>	<p style="text-align: center;">Please initial either Yes or No</p> <p style="text-align: center;">Yes No</p> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
<p>I understand that I will not be receiving any feedback unless a genetic alteration with relevance to my family's health has been identified with very high confidence and confirmed by an expert team.</p> <p>If this has been identified in the collected samples I would like to receive feedback.</p>	<p style="text-align: center;">Yes No</p> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/> <input type="checkbox"/>
Informing your doctor of your involvement in the study and linking to your medical records	
<p>I understand that the information held and maintained by The Health and Social Care Information Centre and other central UK NHS bodies may be used in order to help contact me or provide information about my health status.</p>	<input type="checkbox"/> <input type="checkbox"/>
<p>I agree to my healthcare provider and/or doctor (GP) being informed of my involvement in The Cleft Collective.</p>	<input type="checkbox"/> <input type="checkbox"/>



My GP's name: <input type="text"/> My GP's address: <input type="text"/>	<input type="text"/> <input type="text"/>
I authorise my healthcare provider and/or doctor (GP) to provide my medical records to The Cleft Collective.	<input type="text"/> <input type="text"/>
Other consents	Please initial
If at any point during the study I lose capacity to consent, I agree that my data and biological samples already collected can be retained and used in the study.	<input type="text"/> <input type="text"/>
I understand that if I wish to withdraw from the study in the future, I agree that the biological samples may be retained and used unless I specifically request they are destroyed. In this instance, we will make every effort to do so and ensure that no further analysis is conducted on your samples.	<input type="text"/> <input type="text"/>
I understand that responsible individuals may look at sections of my study and medical records. This will only be where it is relevant to taking part in this research. These individuals will either be representatives from the research sponsor, ethics committee or carrying out research monitoring.	<input type="text"/> <input type="text"/>

I agree to take part in this research

Name:

Signature: Date: / /

Name of witness:

Signature: Date: / /

(Witness can be a researcher or healthcare worker)

Witness not essential

