_	The Cleft Collective Cohort Version 1_18.02.2013	Studies
	ID LABEL	

Consent Form for Parents with an Antenatal Diagnosis

Your name:																						
Your date of birth:]/[/																	
Address:																						
	If y	ou a	ire h	арр	y fo	r us	to c	ont	act	you	in tl	nis v	vay,	plea	ase (give	us y	/our	:			
Telephone number:																						
]						
Mobile number:																						
Telephone number: Mobile number: Email address:																						

We will **not** share your contact details with a third party.

For each statement please initial in the box if you give consent. Thank you.

Your involvement in the study	Please initial
I confirm that I have read and understood the information sheet dated 16/04/2013 (version 2) and have had the opportunity to ask questions.	
I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.	
I understand that any information about me will be kept confidential.	
I understand that The Cleft Collective would like to keep my contact details so that they can contact me in the future about this study and to keep a record of my involvement in the study.	
I would like to be contacted about other cleft studies that I could take part in.	
I understand that donated saliva and cord blood will be considered a gift but I will have the right to withdraw permission for analysis.	
I understand that all the information and biological samples given to The Cleft Collective will be stored and analysed for research purposes only.	



I understand that my saliva and cord blood samples will be stored in Bristol but these sam 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.		
I understand that my anonymous samples and data will only be shared with researchers vare conducting projects approved by a research ethics committee. Researchers have no a to my personal information.		
Biological samples and Questionnaires		Please initial
I agree to The Cleft Collective collecting a saliva sample from me. I agree to my saliva bein stored for research, including detailed analysis of my whole genome.	ng	
I agree to The Cleft Collective collecting a sample of umbilical cord blood following the bir my child. I agree to my child's umbilical cord blood being stored for research, including detailed analysis of their whole genome.	th of	
I understand that the information from questionnaires I complete will be used for research purposes only and I cannot be identified from this information.	h	
I agree to my data and samples being stored and analysed for future cleft related research has been ethically approved.	n that	
Feedback	Please ini Yes	itial either or No
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.		
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	Yes	or No
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. If this has been identified in the collected samples I would like to receive feedback. 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.	Yes	or No
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. If this has been identified in the collected samples I would like to receive feedback. 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	Yes	No
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. If this has been identified in the collected samples I would like to receive feedback. 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.	Yes	No
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. If this has been identified in the collected samples I would like to receive feedback. 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. If this has been identified in the collected samples I would like to receive feedback. Informing your doctor of your involvement in the study	Yes	No No Please
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. If this has been identified in the collected samples I would like to receive feedback. 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. If this has been identified in the collected samples I would like to receive feedback. Informing your doctor of your involvement in the study and linking to your medical records 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.	Yes (No No Please



My GP's name: My GP's addess:															
I authorise my healthcare provider and/or doctor (GP) to provide my medical records to The Cleft Collective.															
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.															
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.															
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.															
I agree to take part in this	resea	rch													
Name:															
Signature:										Date:	,	′	/	'	
Name of witness:										Date:				,	

(Witness can be a researcher or healthcare worker)

Witness not essential

