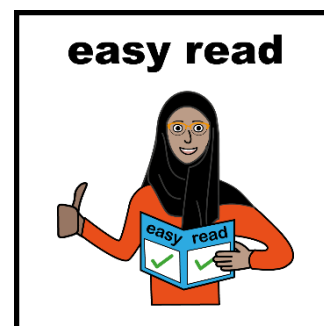


Improving outcomes by addressing variation at the end of routine care for young adults born with cleft lip and/or palate

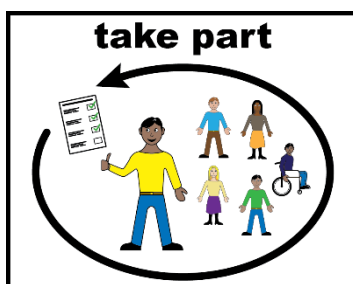


## Research Clinics Information

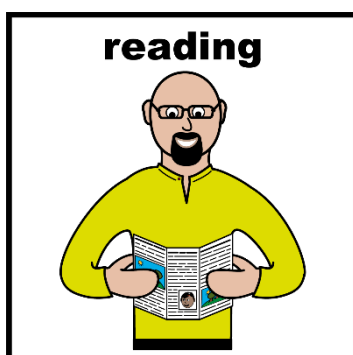


**This information is about the  
Cleft@18-23 study.**

It is a research study for people  
aged 18 to 23 who were born with  
a cleft lip or palate.



We think you might like to take part.



Take time to read it.

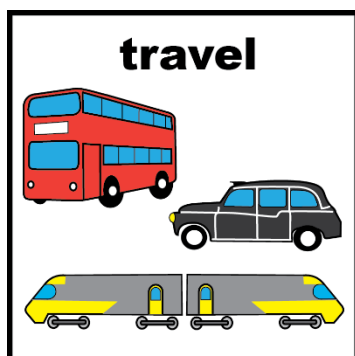


Talk to someone you know about it.

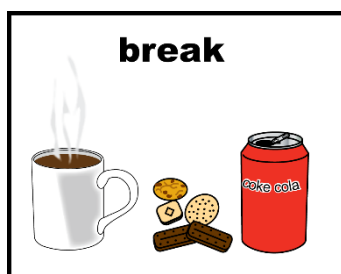
## If you take part, we will give you:



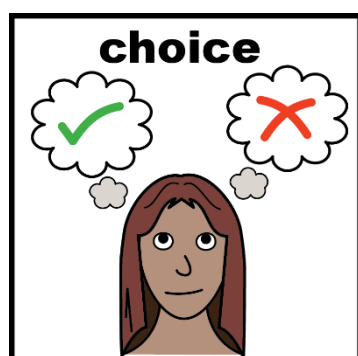
- a £50 gift voucher as a thank you



- money back that you spent to get to the clinic



At the clinic we will give you a drink and a snack



It is up to you if you want to take part, and you can change your mind. It will not change your care.



Information in this leaflet:

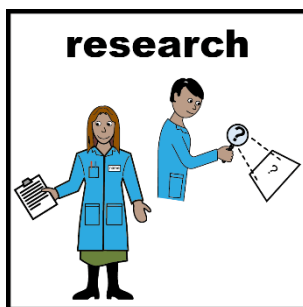
1. What the study is about
2. what you would do at a clinic
3. what to do next if you want to be part of the study



## What the study is about



The Cleft@18-23 study is being run by a Study Team at The University of Bristol



We will work with people born with a cleft lip or palate.



You might have had a lot of treatment as you were growing up.



We want to know about what the end of your treatment was like for you.

We also want to know about your life after your treatment finished.

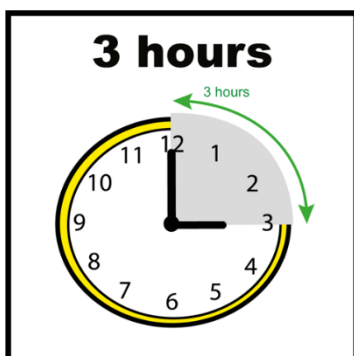
## 2

### What you would do at the Clinic



We will ask you to come to the hospital nearest you that is doing the research.

This might not be the hospital closest to where you live.



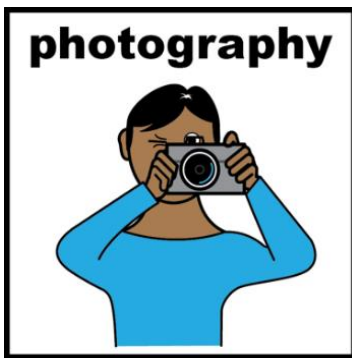
It will be on one day and you will be at the hospital for about 3 hours.

## At the Clinic



You will be asked to answer some questions on an electronic tablet:

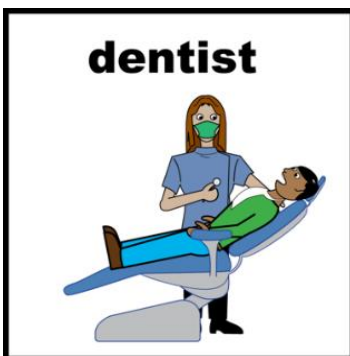
- About you
- About your life
- About how you feel



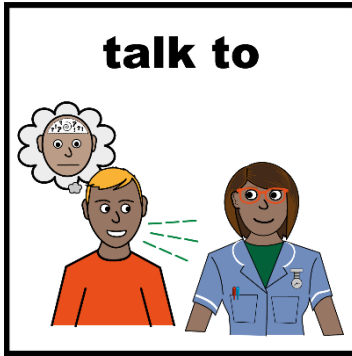
You will be asked to have your photographs taken



You will be asked to do some talking so we can hear your speech and have your hearing checked

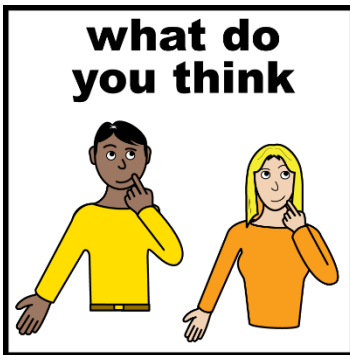


You will be asked to see a dentist who will look in your mouth and check your teeth

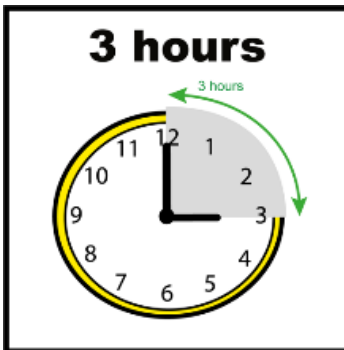


You will also be able to talk to someone about how you are feeling.

This bit will not be part of the research.

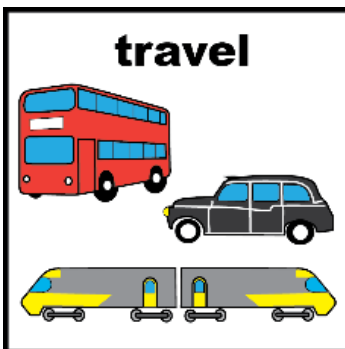


### Things you need to think about carefully

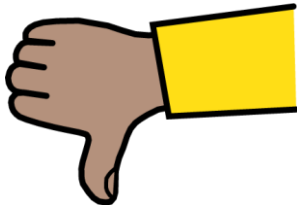


Taking part in the study will take up your time.

You will have to travel to the hospital and the day may make you tired.



This is why we will give you a £50 gift token and help with your travel.



Some people do not like photos and people looking at their teeth. That is OK.



There will be people there to help you. You can ask for all the help you need on the day



You can bring someone you know with you.

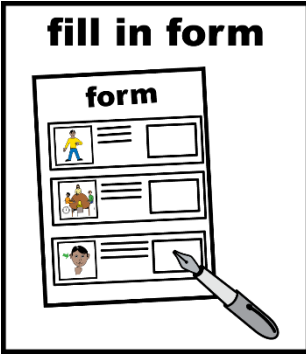


Taking part means you may help lots of people who will be born with a cleft lip or palate.

3

## What to do next if you want to be part of the study

### fill in form



You will need to fill in a form.

Ask for help with this if you need it.



You can do this form on a computer or ask for a paper form.

### about you



This form will ask you questions about:

- You
- your cleft
- and where you live.

It will help us know if you are the right person for the study



## What happens then?

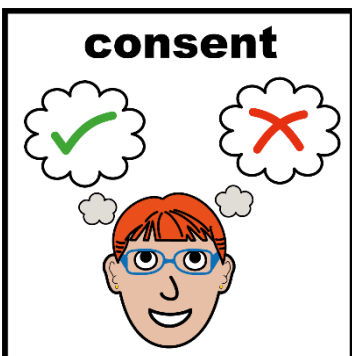


We will contact you to let you know if we think you the right person for the study.



We will ask you to come to the hospital nearest you that is doing the research.

This might not be the hospital closest to where you live.



We will ask you to fill in a form called a consent form.

This form says that you are happy to take part.

We will answer any questions you have.



We will also ask you some more things. We will need to know your name, where you live, what sort of cleft you were born with, whether you are male or female, how old you are, and your ethnicity.



You will then:

- Answer some questions on an electronic tablet
- Have some pictures taken
- Record you speaking and check your hearing
- Have your teeth checked

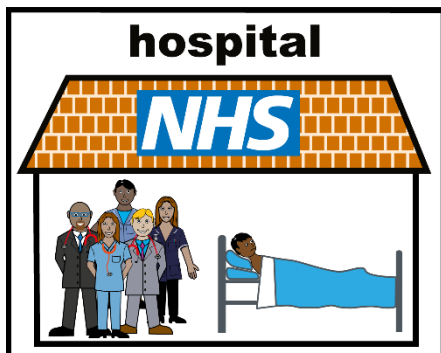


You can also talk to someone about how you feel



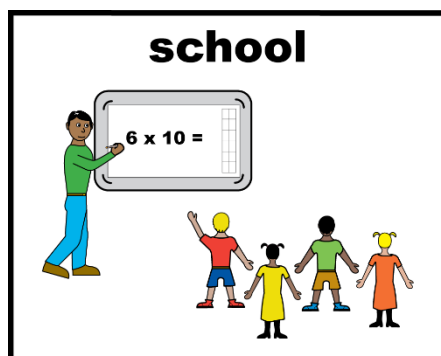
At the end of the clinic, we will give you a voucher to say thank you.

## Looking at your records.

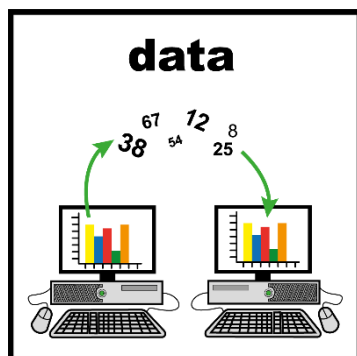


We will ask you if we can look at your hospital records.

This will help us understand what treatment you had.



We will also ask you if we can look at your school records. This will help us understand how going to school was for you.



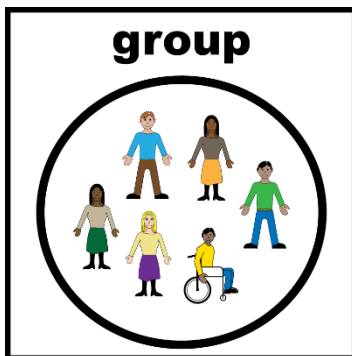
Some data (or information) about the treatment you had might be on a computer database called CRANE. We will ask you if we can check and look at your records on there too.

You can find out more about CRANE on this website: <https://www.crane-database.org.uk/>

## What happens after the study?



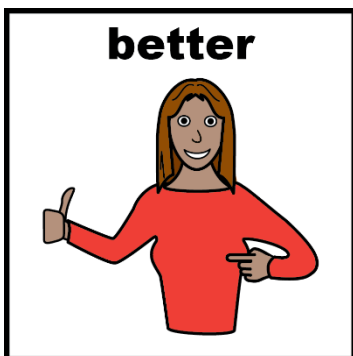
We will look at your answers and all the other things you have done at the hospital.



We will look at other people who have taken part in the study.

We will see if groups of people are different or the same in how they feel, or how they look or how they sound.

We will use all the information to:



- Talk to groups of staff who work at hospitals, looking after young people born with a cleft
- Talk to groups of other young people born with a cleft
- Work with these groups to make things better for young people after their treatment finishes.

## Keeping your information safe.



We will keep everything you tell us and give us safe. Only people working on the study will see your details.

We will need to keep some of the things you give us for a long time to help us finish our study.



We will follow the rules to protect your data (or information).

The rules we will follow are called GDPR.

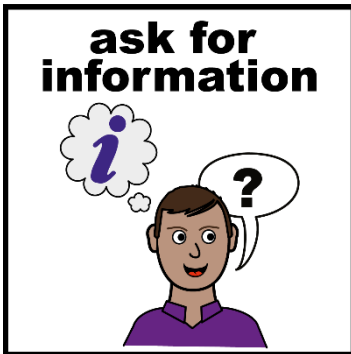
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**You can find out more information  
on what GDPR is in this leaflet:**

<https://www.sldo.ac.uk/media/1821/easy-read-gdpr-info-sheet.pdf>

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## Finding more information about Cleft@18-23 Research



There is more information about this study and how we make sure you are safe during the study.

You can find this in a different leaflet.

Please ask us or someone you know to find out more.



You can get in touch with us by:

- Email: [cleft-1823@bristol.ac.uk](mailto:cleft-1823@bristol.ac.uk)
- Phone: 0117 3310025
- Mobile: 07484 515 858



You can also visit our website at [www.bristol.ac.uk/cleft18-23](http://www.bristol.ac.uk/cleft18-23) to find out more about the study and any latest updates.