

D-CYPHR | The DNA, Children +  
Young People's Health Resource

# Information for young people aged 9–12



V3.0, 04 April 2024

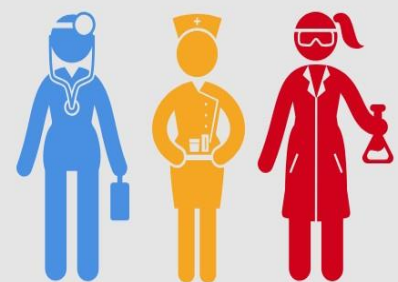
## Contents

What is the project about?.....	3
What will I have to do?.....	3
How will my saliva (spit) help? .....	4
What happens after I join? .....	6
How do I join?.....	8

## What is the project about?



Many people live with health problems. We are a team of doctors, nurses and scientists working to find out why people become unwell and how we can improve everyone's health.



We would like to ask you to help us with research into why people become unwell by joining D-CYPHR, the DNA, Children + Young People's Health Resource.

D-CYPHR is part of the **National Institute for Health and Care Research (NIHR) BioResource**.

The **NIHR BioResource** is a project helping to understand how our bodies work and why some people develop health problems.

We are asking young people and adults if they would like to help. Your parent/guardian will also need to agree that you can take part.

## What will I have to do?

If you would like to take part, we will ask you to answer some questions about yourself, either online or on paper. We will ask you to give us some of your saliva (spit) by spitting in a tube.



We will use your saliva (spit) and the answers you give to help us understand rare and common diseases. We want to know how we can improve treatments or prevent these conditions.



You don't have to take part and you can ask us any questions you like before deciding.

## How will my saliva (spit) help?

We want to find out more about how our bodies work.

Our bodies are made up of millions of tiny building blocks called **cells**.

Inside each cell is a set of instructions on how to make our bodies work. These instructions are called **DNA**.

DNA in the cells in your eyes makes your eyes the colour that they are, and the colour of your hair depends on the DNA in your hair cells.

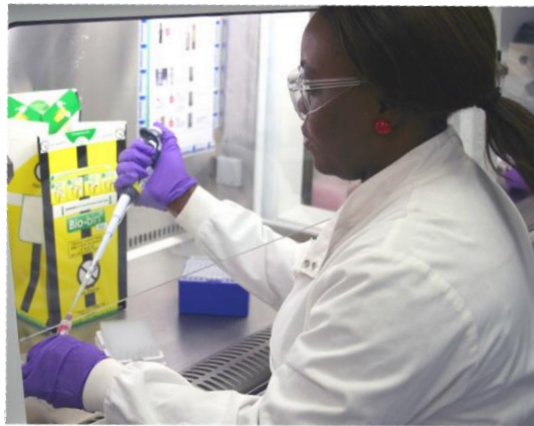
DNA is in every cell, and it is important to keep cells working normally and keep us healthy. We can find your DNA in cells in your saliva.



Scientists can look at DNA to understand more about why things go wrong. They use this to try to find treatments and help improve people's health.

## What happens after I join?

How we will use your saliva (spit) sample:



Your saliva is given a unique number not your name. We call this being 'de-personalised'.

Your saliva is taken to our laboratory, where scientists will start to look for your cells and DNA. Your samples are stored to use in future research.



We will also collect information such as your name, address, and date of birth. Only people who need to see this will have access to it.

**Your samples and information will be stored securely and only be used to help with medical research.**

You and your parent/guardian can find out more about how we use data on our website: <https://bioresource.nihr.ac.uk/about-us/gdpr/>

### How we might ask you to help in the future:

We might also invite you to help with other research projects.


- we will let you know why we have invited you to help
- you can choose whether you want to take part

It's ok if:



- you change your mind and don't want to take part anymore
- you don't want to be invited to studies in the future


If you change your mind and stop taking part you don't have to tell us why.

## How do I join?

<p>Look at the website</p> 	<p>If you and your parent/guardian(s) would like to know more about the project, you will be given a link to the D-CYPHR website.</p> <p><u>There you will be able to:</u></p> <ul style="list-style-type: none"> <li>• find out more information</li> <li>• send any questions you have to the project team, by email or telephone</li> </ul>
<p>Ask questions</p>	<p>You can ask us any questions you like, and you don't have to agree to take part.</p>
<p>Read information</p>	<p><u>This will include:</u></p> <ul style="list-style-type: none"> <li>• Details about D-CYPHR</li> <li>• A consent form for your parent/guardian(s)</li> <li>• An assent form for you to sign.</li> </ul> <p>If you sign the assent form this will say that you are happy to take part in D-CYPHR.</p>



<p>Complete forms</p>	<p>If you choose to join online, your parent/guardian(s) will be sent an email with forms for you both to complete.</p> <p>If you are sent the forms in the post, you and your parent/guardian will fill out the forms and then send these back to us.</p>
<p>Spit in a tube</p>	<p>Next, we will send you a tube to collect your saliva in.</p>  <p>We will ask you to spit or dribble into the tube in the sample pack and return it to us.</p>
<p>Answer questions</p> 	<p>We will ask you to answer some questions about yourself and your family (online or on paper).</p> <p><u>You will be asked about:</u></p> <ul style="list-style-type: none"> <li>• Your medical history</li> <li>• How you spend your free time, your friends, your family, and school – you can decide if you want to fill this one out or not.</li> <li>• Fill in forms with a parent/guardian’s help</li> </ul>

<p>Give us permission</p> 	<p>We will also ask for you and your parent/guardian's permission to see:</p> <ul style="list-style-type: none"> <li>• parts of the information held in your doctor's notes and</li> <li>• your school records and</li> <li>• any health or social worker records.</li> </ul> <p>This will help us understand the other things that affect young people's health.</p>
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*Thank you for taking the time to read the information sheet and thinking about taking part in the DNA, Children + Young People's Health Resource.*

**If you were sent this information sheet in the post, complete the assent form on the next page.**

## Assent Form (for children to fill out)

Would you like to take part in our research project?  
(The DNA, Children + Young People's Health Resource)

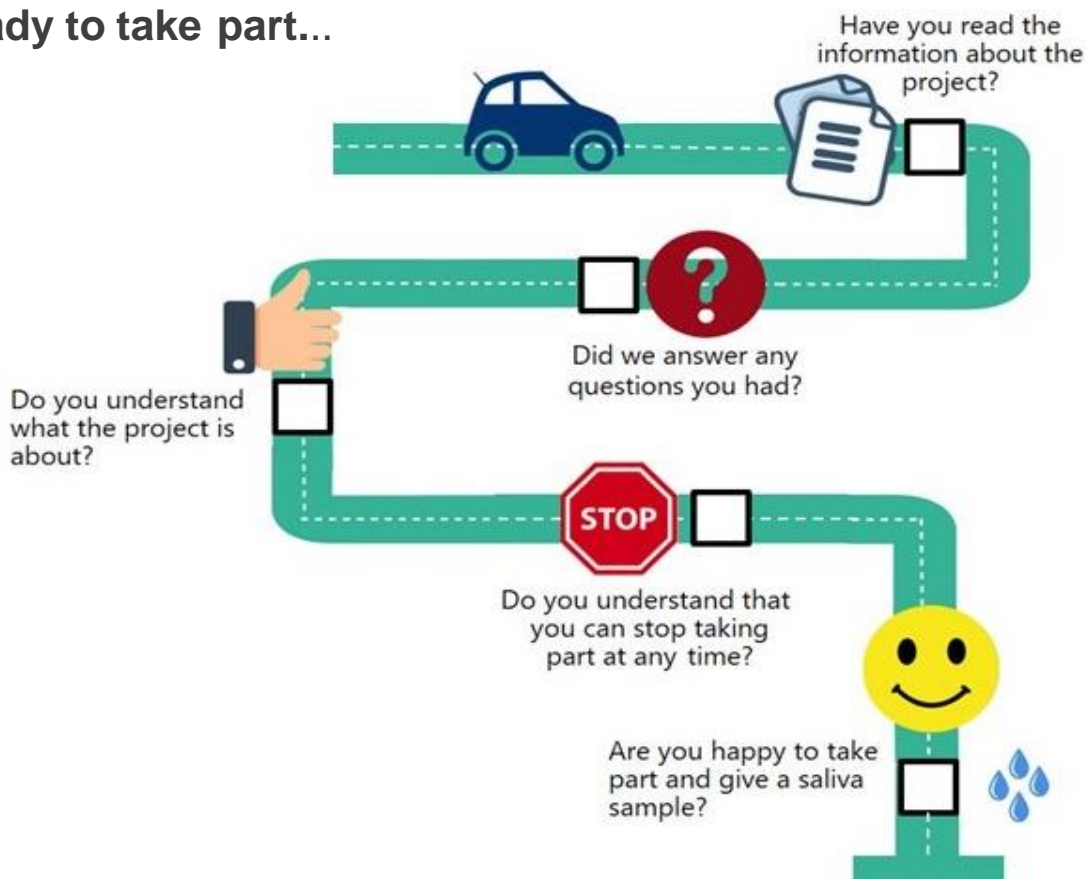
**This form  
can be  
completed  
online**

Please tick one of the boxes

YES   NO  

*Thank you for reading about our research. You don't need to do anything else.*

Follow the road below and tick the boxes to make sure that you're ready to take part...



Please write your name to show us that you are happy to take part

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Please write your full name

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Date