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

Information for young people aged 13–15

V3.1, 16 Jan 2025

Contents

What is the project about?

Many people are living with a long-term condition such as diabetes, heart disease or mental health conditions. Living with a chronic disease has a major impact on a person and their family. We are a group of scientists and healthcare professionals who are working to improve diagnosis and treatment of common and rare diseases.

We would like to ask you to help with this research by joining D-CYPHR. D-CYPHR stands for the DNA, Children + Young People's Health Resource. This programme is part of the **National Institute for Health and Care Research (NIHR) BioResource.**

The **NIHR BioResource** is a project aiming to improve understanding of long-term health conditions. We are doing this by looking at how genes and environment can impact a person's health. When we talk about 'environment' we mean the things that make up your day-to-day experiences. More about how we look at genes is explained on page 5 of this information sheet.

Today there are around 1.7 million children and young people in England with a long-term health condition, and one in six children could have a probable mental health condition. Your contribution will be helping valuable research.

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 (whichever you prefer) and give us a small saliva (spit) sample.

We will then use your saliva and the information you give us to help better understand rare and common diseases. We will look at how we can improve treatments and care, or prevent serious illness in the future.

You don't have to take part and you can ask us any questions you like before deciding. As you're under 16 years of age, your parent/guardian will also need to agree that you can take part. When you turn 16, we will ask you if you want to re-consent to the project.

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 cells. Each cell contains DNA, which provides the cells with instructions on how to work. DNA determines things like your hair and eye colour. Your genes are made up of DNA. We will take your DNA from your saliva.

Scientists look at DNA and genes to understand how they influence disease, to help us understand why things go wrong and how to improve treatments and people’s health.

What happens after I join?

How we will use your saliva (spit) sample:

Your saliva sample is given a unique number and will be taken to our laboratory, where scientists will extract your DNA. Your sample is stored and will be used in future research.

What happens to my data:

We will collect personal information about you. This includes things like your name, address, and date of birth. Only people who need to see this will have access to it.

Your samples and answers to the questionnaires will be given a unique ID number not your name. We call this being ‘de-identified’.

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

More information about how we use your data can be found here:

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 studies, if we do we will:
- let you know why we have invited you to help
- ask you whether you want to take part

You can let us know at any time if you change your mind about taking part in D-CYPHR or being invited to studies in the future. You don't have to give a reason.

How do I join?

If you and your parent/guardian would like to know more about the D-CYPHR project, you will be signposted to our website where you can find out more information and submit questions to the project team.
https://bioresource.nihr.ac.uk/dcyphr/

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

You can choose to join online or receive an information pack in the post.

A D-CYPHR information pack will include:
- Written information about the study

- The consent forms for your parent/guardian to sign
- The assent form for you to sign (if you wish to take part)

1. If you choose to join online, your parent/guardian will be sent an email with forms for you both to complete to confirm your agreement. 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.

2. Once we have received these forms (online/post), we will send you a tube to collect your saliva in.

3. We will ask you to spit or dribble into the tube in the sample pack.

4. Put the filled saliva tube into the return packaging provided and post it back to the BioResource. It will be free to send as the postage is pre-paid. The package can be put into any Royal Mail post box or dropped off at a post office. Samples will be returned to us via tracked courier or tracked Royal Mail.

5. We will ask you to answer some questions about yourself and your family. Again, these can be done online or on paper – it's your choice. If you choose to complete them online, your parent/guardian will be sent an email. There are two questionnaires:

- One will ask about your medical history – we ask everyone to fill this out with their parent/guardian’s help.

- The second will ask about your friends, your family, your school and how you spend your free time – you can decide if you want to fill this one out or not. If you decide to fill it out, we will ask your parents/guardians to fill one out as well.

6. We will also ask for you and your parent/guardian’s permission to view parts of the information held in your doctor’s notes and your school records. If you have a social worker, we might ask to see information in their records as well. This will help us understand the other things that are affecting young people’s health.

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 young person to fill out)

This form can be completed online

Would you like to take part in our research project?

(**The DNA, Children + Young People's Health Resource**)

Please tick one of the boxes	**YES**	**NO**

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

Read each statement and tick the boxes to make sure that you're ready to take part…

Statement:	**Tick Below**
Have you read the information about the project?	
Did we answer any questions you had?	
Do you understand what the project is about?	
Do you understand that you can stop taking part at any time?	
Are you happy to take part and give a saliva sample?	

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

_ _
Please write your full name

_ _ _ _ _ _ _ _ _ _ _ _ _ _ _
Date