

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

# Information for young people aged 13–15



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## 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, 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 studying people's genetic make-up and the role of genes in keeping us healthy.

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, and 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 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 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.



### 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 or being invited to studies in the future, and you don't have to give a reason.

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

## How do I join?

If you and your parent/guardian(s) would like to know more about the project, you will be signposted to our website where you can find out more information and submit questions to the project team.

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.

### This will include:

- Written information about the study
  - The consent forms for your parent/guardian(s) 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(s) 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.
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 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. 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)

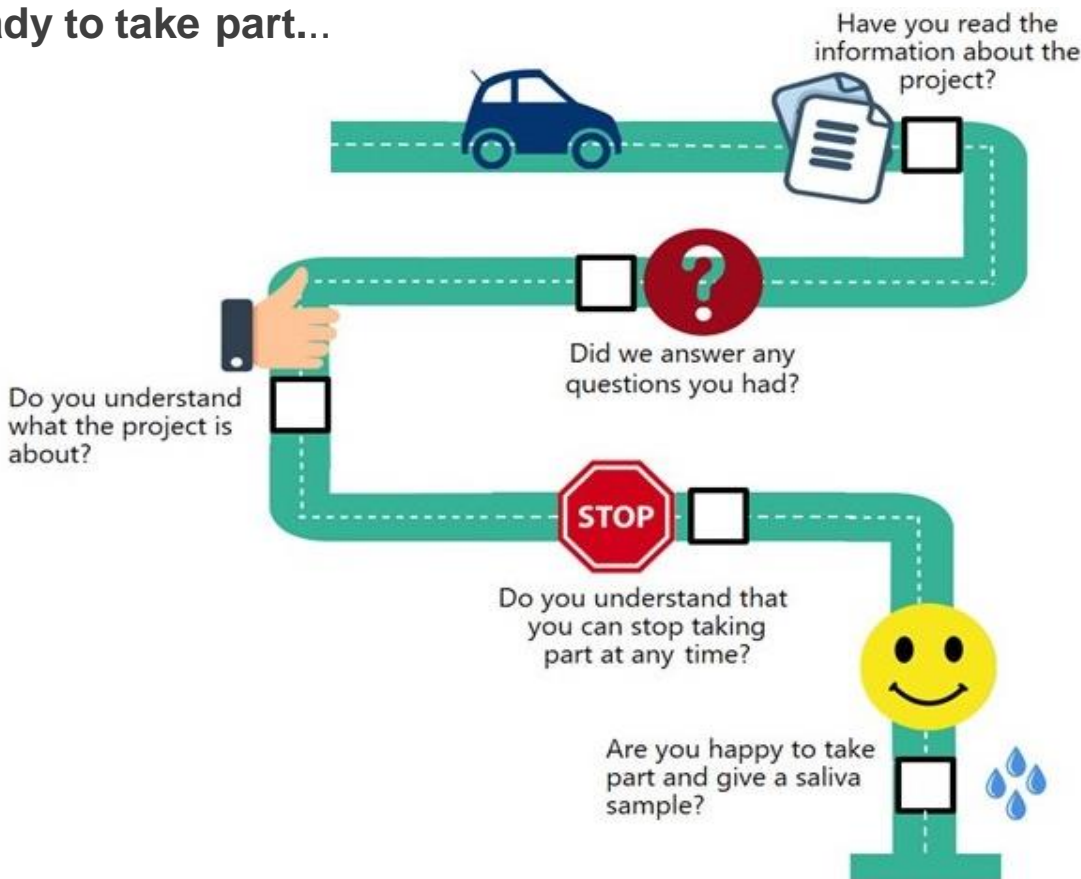
Please tick one of the boxes

YES

NO

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

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