

Frequently Asked Questions for Young People (aged 13-15 years) in Educational Settings

V1.0, 30/04/2021

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1. What is this project about?

The NIHR BioResource is a project helping to understand how our bodies work and why some people get sick and others don't. Young people between 11 and 15 years old are being asked to join and help. Young people who join the BioResource will be asked to take part in other research studies in the future. They can decide if they want to take part in these studies, or not.

More information about the NIHR BioResource can be found here: [NIHR BioResource Home Page](#). You can also view this animation which gives a good summary: <https://youtu.be/BR0mvJh7Czk>.

2. What kind of research do they do?

Our bodies are made up of millions of cells. Inside each cell is a set of instructions on how to make our bodies work. These instructions are called DNA. DNA determines things like your hair and eye colour. The instructions contained in your DNA make up your 'genes' or 'genetic

code'. DNA is in every cell and it is important to keep cells working normally and keep us healthy. The BioResource helps doctors and scientists learn about differences in people's DNA. By looking at DNA, it can help us to understand why things go wrong sometimes and people get sick, and how we might make people better.

3. Why have I been asked to join?

It's important that we understand why some young people get sick and others don't, and the BioResource is asking young people who aren't sick, as well as those who have illnesses, to help with the project.

4. What will I need to do?

The key steps to join the NIHR BioResource are:

- First, we will invite you to an information session, where we will talk to you about the project and ask if you want to help. Your parent/guardian will also need to agree that you can help. You can ask us any questions you like and you don't have to agree if you don't want to.
- If you and you parent/guardian agree, we will ask you all to complete a form letting us know.
- We will send you some questions to answer about yourself and your family. You may need to complete this with help from your parent/guardian.
- We will also send you a saliva pot and you will be asked to spit into it. We will ask your parents to post it back to us, and we will then be able to look at the DNA in your spit.
- We will also ask for your 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. We may contact your doctor or use your NHS number to view your records with your permission.
- We might write to you and your parent/guardian sometimes to ask if you want to take part in more research. Each time we will give you lots of information about what you would need to do, and you can decide with your parent/guardian if you want to take part. It's OK to say 'no' at any time.

5. Why do you need to access my health and education records?

We know that our health is affected by lots of different things like our genes, the environment and how school is going. When we talk about 'environment' we mean the things that make up a young person's day to day experiences – it can include things like where you live, what part of the country you live in, if it's rural or in a city, the structure of your family, or the school you go to. Research shows us that a person's genes can affect how they cope with different environments. We want to look at how this affects young people's health and wellbeing. We know health and wellbeing can be affected by your environment, for example, family life at home, where you live, and how you do at school. We would like to invite young people like you to take part in studies looking at how you feel and your mood, the variety of things that affect it, and how your genes can play a part. Your social care and education records can help us study these links.

6. What if I have more questions?

The BioResource will invite you and your parent/guardian to a meeting (for example to a video call) to tell you more about what we do and this will help you decide if you want to take part. You and your parent/guardian will be able to ask questions during this call. You don't need to have your camera turned on if you don't want to.

7. What happens to my saliva?

Your spit is given a unique study number and will be taken to our laboratory, where scientists will start to look for your cells and DNA. Your samples are stored for future research.

8. I would like to take part, what do I do next?

It is very important that both you, and your parent/guardian are happy for you to take part in the BioResource. After you attend the [video call/meeting], your parent/guardian will be asked to give permission for you to take part by signing a form – this is called giving 'consent'. You will also be asked if you are happy to take part – this is called giving 'assent'.

If your parent/guardian does not give permission you will not be contacted about taking part. You and your parent/guardian can change your mind about taking part at any time and you don't have to tell us why.