

Frequently Asked Questions for Parents/Guardians (For use in educational settings)

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1. What is the NIHR (National Institute for Health Research) BioResource?	2
2. What kind of research is carried out?	2
3. Why is genetic research important?	2
4. Why are you including young people in the research?	3
5. Why are you including young people with no current illnesses?	3
6. What will me and my child(ren) need to do?	3
7. Why do you need to access my child(ren)'s health and education records?	4
8. What if I have more questions?.....	4
9. What happens to my child(ren)'s saliva?	5
10. What happens to my child(ren)'s DNA and the information stored by the BioResource?.....	5
11. We would like to take part; how do I give permission for my child(ren) to participate?...	5
12. What is the difference between 'consent' and 'assent'?	6
13. How long will my child(ren) be involved in the BioResource?	6
14. What happens if me or my child(ren) decide we do not want to participate anymore?...	6

1. What is the NIHR (National Institute for Health Research) BioResource?

The NIHR BioResource provides a way for researchers to contact individuals who have agreed to volunteer to help with research studies. Each person who agrees to help, provides information related to their health and lifestyle, as well as biological samples including DNA. This information is stored securely by the BioResource.

The BioResource can contact people on behalf of researchers and ask them to participate in research studies based on their personal characteristics, such as their genetics, or whether they have suffered from a particular illness either in the past or currently.

The NIHR BioResource has been active for over ten years and has over 200,000 people volunteering. This includes healthy people and those suffering from illnesses such as Inflammatory Bowel Disease, Depression and Anxiety, and COVID-19.

Further 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 is carried out?

Most of the research involves understanding the role that genetics plays in disease. For example, we now know that some people are more likely to respond to certain heart medications depending on their genetics. We also know that genetics makes some people more likely to get some forms of cancer earlier in life. Researching this means we can develop ways to identify cancers earlier, giving more people a better chance of a full recovery. Researchers want to explore the genetics of a range of diseases to understand more about how to identify illnesses early, what causes illnesses, and what treatments work best for which people.

3. Why is genetic research important?

Genetic research is seen as one of the key opportunities to transform medicine and improve the health of our nation in the coming years. A lot of progress has been made already. For example, we are able to test the genetics of cancers and choose specific drugs that are more likely to cure people. We can also now carry out rapid tests for children with diabetes to select which medication will work best for them. This means that many are able to avoid painful daily injections and have tablets instead. We are also starting to understand that environmental factors, such as where you live or the experiences you have in the first 25 years of life can interact with your genetics and affect the severity of diseases you get later in life – such as heart disease or cancer. Understanding how genetics makes a person more likely to get a disease, or suffer from a more severe form, and to understand which medicines will work best for them depends on researchers being able to study our genetic makeup.

4. Why are you including young people in the research?

A lot of the research in the field of genetics has focussed on common adult diseases. However, genetics also plays an important role in many childhood diseases. For example, we know that genetics can affect the likelihood of getting infections as a child or developing mental health problems early in life. Although there are a lot of volunteers already participating in genetic research through the BioResource, these are mainly adults. Because it is so important to study childhood diseases, we are now focussing our attention on identifying young people between 11 and 15 years old who would like to help in these research studies.

To make all this possible the NIHR BioResource is launching a '*Young People's (YP) BioResource*' (abbreviated YP-BR).

5. Why are you including young people with no current illnesses?

Perhaps one of the most important groups in any research study is the group of people who are called the 'healthy control group'. This is a group of individuals with no specific disease who act as a comparison group for people with a known illness. By having a group of 'healthy controls', researchers can compare different things in the 'disease' and 'healthy control' groups to understand what is different about those who have the illnesses.

One of the first things that the YP BioResource aims to do will be to create this important 'healthy controls' group for young people. So, we are starting by inviting young people from the general population to join the programme, with their parent's/guardian's permission.

6. What will me and my child(ren) need to do?

The key steps to join the NIHR YP BioResource are:

- First, we will invite you to an information session, where we will talk to you and your child(ren) about the project and ask if you want to help. You can ask us any questions you like and you don't have to agree if you don't want to.
- You and your child(ren) give permission to take part by completing the consent forms.
- Your child(ren) will be asked to fill out a questionnaire about their health (e.g. general health and any illnesses they have suffered in the past or currently), personal characteristics (e.g. height, weight, if they are left or right-handed), their lifestyle (e.g. if they are vegetarian, and how much exercise they take). They will have the option to complete a second questionnaire about their free time, family, friends and school.
- Your child(ren) will also be asked to dribble into a saliva pot. You will be asked to post this back to the BioResource in a pre-paid addressed package that just needs to be put into the post box. We will use the saliva sample to analyse your child(ren)'s DNA and the details of your child(ren)'s genetics will be stored by the BioResource.
- We will also need your permission to access relevant sections of your child(ren)'s medical, social care and education records. We may contact their GP or use their NHS number or other personal details (e.g. name, date of birth) to access these records.

Once you have consented (given permission) and your child has assented (agreed they want to participate), your child(ren) will become members of the NIHR YP BioResource. People who join the YP BioResource can be contacted and invited to take part in specific studies. Participating in a study might involve different things, for example, answering more questionnaires about a specific issue or additional tests, for example, a blood test. For each study, young people and their parents/guardians will be given all the details and they can choose whether they wish to participate or not. Involvement in these additional studies is completely voluntary – there will be no pressure to take part, and young people can choose not to participate at any time.

7. Why do you need to access my child(ren)'s health and education records?

We know that our health is impacted by lots of different things like our genes, the environment and how work or 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 they live, what part of the country they live in, if its rural or in a city, the structure of their family or the kind of school they go to. Research is showing that a person's genetic makeup can affect how they cope with different environments. We want to study how this affects health and wellbeing.

One example of how we might use medical records is the study of COVID-19. Thankfully, COVID-19 infection affects very few children, however a small number do get the illness, and they can also become unwell with it. Even though most children don't get COVID, we don't know whether vaccinating all children will stop those very few from catching it. By linking to participants' health records, we can learn about whether they have had COVID, if they get it severely, who has been vaccinated, and whether their genetics plays a role in this.

Another example is young people's health and wellbeing. We know it can be affected by environmental things like health, home circumstances, where they live, and how they do at school. We would like to invite young people to take part in studies looking at mood and the range of things that affect it, and how genetics can play a part. A person's social care and education records can help us study these links.

So far we have started to explore this with adult COVID, mental health problems and eating disorder studies – we now want to understand how it might work for young people.

8. What if I have more questions?

To learn more about the BioResource and help you make a decision about whether to participate or not, you and your child(ren) will be asked to attend an information session that will provide explanations on how the research works and what is involved. This will be held via a video-conference, and will include up to 25 families who are interested in learning more about the research. You will not be required to have your camera on during this session. If

you register to attend the information sessions, you will be sent a participant pack that contains further information. This is so that you can see what is involved in more detail in advance of the information session. The information session will involve a 15 minute presentation by the BioResource team and then allow for up to 30 minutes of questions from families. At this point the information session will have finished, and families can leave without missing any information. However, if any families have any other questions that have not been answered, we will continue the session for another 30 minutes.

9. What happens to my child(ren)'s saliva?

Your child(ren)'s saliva sample will be assigned a unique study number and will be stored in a laboratory. The saliva in the sample pot will be analysed by extracting the DNA to get a reading of your child(ren)'s genetic profile. Any remaining DNA or saliva will be stored at the laboratory for future use by the BioResource.

10. What happens to my child(ren)'s DNA and the information stored by the BioResource?

DNA samples will be stored and other researchers may seek access to samples and related data, but your and your child's personal details will never be released to researchers without your knowledge. Samples will be kept in secure locations.

Best ethical and legal practice will be followed to ensure that your and your child(ren)'s information will be handled in confidence. Samples will be labelled with a unique sample study number and information from genetic and other tests will be stored separately from personal details in secure databases. Access to personal details will only be available to necessary members of the NIHR BioResource and regulatory authorities who check that this study is being carried out correctly.

11. We would like to take part; how do I give permission for my child(ren) to participate?

The steps to giving permission are:

- You and your child(ren) attend the virtual information evening (or face-to-face session if they become available).
- You give permission for your child(ren) to participate by giving 'consent' to join the BioResource.
- Your child(ren) agree(s) to participate by giving 'assent' to join the BioResource.

Children of parents/guardians who do not consent will not be invited to participate. You can withdraw consent at any point and your child(ren) will be removed from the BioResource.

12. What is the difference between ‘consent’ and ‘assent’?

In England, children under 16 years of age are not legally able to agree to participate in medical research (called ‘consenting’) without their parent/guardian’s agreement. Instead, parent/guardians consent to their children being involved and we also get agreement from the child – this is referred to as ‘assent’. So, for a young person to participate we need both the parent/guardian’s ‘consent’ and the child’s ‘assent’. We need to have both of these documented in writing.

13. How long will my child(ren) be involved in the BioResource?

Once a child has agreed to participate, they will remain a volunteer in the BioResource either until they turn 16 years old or if they decide not to participate anymore. When a child turns 16, they will be re-contacted and asked to re-consent to participation for themselves, as they will no longer need their parent/guardian’s permission. As the parent/guardian of a member of the YP BioResource, you yourself will not be a member of the BioResource and you will not be required to provide a sample nor will we access your health or other records.

14. What happens if I or my child(ren) decide we do not want to participate anymore?

A young person can decide not to participate at any time. If they tell us they no longer want to participate, we will contact the child and parent/guardian to ask if they want their samples we centrally hold to be destroyed, and if they want their data to remain in the BioResource or not. However, if a child (through their parent/guardian) has been contacted about joining additional research studies, has chosen to participate in them and the data has already been analysed, we will not be able to remove their data from those research studies.