

# Frequently Asked Questions for Schools

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### **1. What is needed from schools who choose to participate?**

Contacting families via schools is a new way of getting people involved in the BioResource. We want to work with six schools between May 2021 and June 2022 to get advice on the best ways to do this. This will involve up to three meetings or workshops during this time. At least one of these will be in mid-2021. We will initially focus on: 1) understanding the likely barriers to getting young people and parents/guardians involved, 2) fine-tuning the communication materials and 3) understanding the best approach to use to running the information sessions.

In June/July we would like to pilot inviting young people to participate in the BioResource. This will involve the school emailing parents/guardians, using materials developed by Anna Freud Centre and the BioResource. They will be invited to attend an information session online, where we will explain the research and invite young people to get involved and ask parents/guardians if they are willing to give their permission.

### **2. What does the school need to do to qualify for £1,000 and the education session?**

This is still being refined; however, we will ask schools for a senior leadership team member to attend all three of the meetings/workshops. It is likely that we will ask the school to email the parents/guardians to provide them with the pre-prepared information about the study and ask them to register their interest using an online form. We will ask for posters to be put up around the school and for the information to be included in any relevant newsletters or communications to parents/guardians.

### **3. How will we select schools if there are too many applications?**

We are looking for schools that are keen to participate and who are able to assure us that they have capacity to attend the three meetings/workshops. We are aiming to maximise inclusion of young people from a diverse range of backgrounds and so will choose a balance of schools that provide this diversity. For those schools not selected for the first round, we will be aiming to start another round in September 2021. This will involve offering a free teaching session as part of e.g. PHSE/RHSE sessions, but not the financial incentive as it will not involve attendance at the workshops.

### **4. What is the NIHR (National Institute for Health Research) BioResource?**

The NIHR BioResource is a national resource of volunteers who have agreed to help with research studies. Each person who consents 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 and researchers can contact people 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](#).

### **5. What kind of research is carried out?**

Most of the research involves understanding the role that genetics play 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 make 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.

### **6. Why is genetic research important?**

Genetic research is seen as one of the key opportunities to revolutionise 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 make 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 is reliant on researchers being able to study our genetic makeup.

### **7. Why are you including young people in the research?**

Most of the research in the field of genetics has focussed on common adult diseases. However, genetics also play 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*’.

### **8. 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.

The first thing that the YP BioResource aims to do will be to establish 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/guardian’s permission.

### **9. What is involved in participation?**

Young people who agree to help with the research will be asked to provide a sample of their saliva by dribbling into a pot. DNA will be extracted from this sample, analysed and the details of their genetic makeup will be stored by the BioResource. They will also 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. This information will be used by researchers studying particular diseases.

These young people 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 or a brain scan. 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 studies is completely voluntary – there will be no pressure to take part, and young people can choose not to participate at any time.

### **10. How will they get permission from a parent/guardian**

It is very important that a parent/guardian gives permission for their child to participate in the YP BioResource and any future studies. The first step will be to explain the research to parents/guardians and young people in an information session. Parents/guardians will then be invited to give their consent for their child to participate. Young people whose parents/guardians give their consent will be invited to join the BioResource – they will be asked to give assent, or agreement, to participate. Children of parents/guardians who do not

consent will not be invited to participate. The parent/guardian can withdraw consent at any point and the young person will be removed from the BioResource.

### **11. What is the difference between ‘consent’ and ‘assent’?**

In England, young people 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/guardian’s consent to their child being involved and we also get agreement from the young person too – this is referred to as ‘assent’. So, for a young person to participate we need both the parent/guardian’s ‘consent’ and the young person’s ‘assent’. We need to have both of these documented in writing.

### **12. How long will the young people be involved in the BioResource?**

Once a young person 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 any more. When they turn 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. This will be to join the adult BioResource.

### **13. What happens if they decide they do not want to participate anymore?**

A young person can decide not to participate at any time. We will contact the young person and their parent/guardian to ask if they want their samples to be destroyed and if they want their data to remain in the BioResource or not. However, if a young person has been contacted about joining in additional research studies and has chosen to participate, we will not be able to remove their data from those research studies.

### **14. What will young people and parents/guardians need to do?**

To learn more about the BioResource and help them make a decision about whether to participate or not, young people and their parents/guardians will be asked to attend an information session to explain how the research is conducted 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. Families that register to attend will be sent a package in the post that contains written information about the study and the consent forms. This is so that they can read about the details of the study in advance of the information session. The information session will then involve a 15 minute presentation and then allow for up to 30 minutes of questions/insert details of information session if conducted differently for example, face-to-face (*delete as appropriate*)].

If parents/guardians and the young people agree, they will be asked to complete the consent forms, which confirms agreement to participate in the study. They will also be asked to fill out

two questionnaires about themselves and their family, and to provide a saliva sample in a sample pot. They will be asked to post these back to the researchers in a pre-paid addressed package that just needs to be put into the post box.

### **15. What happens to the saliva sample?**

DNA will be extracted from the saliva and will be analysed to get a reading of their genetic profile.

### **16. What happens to the 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 personal details will never be released to researchers without the volunteers' knowledge. Samples will be kept in secure locations.

Best ethical and legal practice will be followed to ensure that volunteers' 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 NIHR BioResource and regulatory authorities who check that this study is being carried out correctly.