



# Children of the 90s

## Genetic material participant information

### Introduction to DNA, RNA and Genes

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Our genes play an important role in defining many characteristics about individuals and some can make us more or less likely to develop many common diseases. We all have a slightly different set of genes in our bodies and different biological mechanisms act to control how our genetic code operates. To help us look at these features and understand varying characteristics and the causes of diseases, we can use a number of techniques to obtain samples of genetic material from blood or tissue samples. The study of genetic material, which includes DNA and RNA, and genes is referred to as genetic research, and work on the biological features operating on our DNA, is called “epigenetic” research.

If you have given us a sample for genetic material in the past, it is useful for us to remind you that we do hold these stocks, what they are used for and to remind you that you can let us know if you have changed your mind. If you are providing a sample for the first time we will create a stock of your genetic material, if you give us consent, and use it for future research.

### What are DNA and RNA and what are genes?

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Genes are the instructions which determine growth and development of all living organisms. DNA and RNA are the chemical languages in which genes are written, we can analyse them to find out your individual DNA or RNA sequence.

As well as looking at your DNA sequence DNA can be used for epigenetics which is the study of biological mechanisms that switch genes on or off – this can vary with time and environment and is not essentially fixed like the code of our DNA.

RNA is a decoded version of our DNA and we can look at genes as they are “expressed” by collection and analysing RNA. Gene expression is a tightly regulated process that controls when proteins are made and also acts as a volume control that increases or decreases the amount of proteins made.

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### Frequently asked questions.

**Q:** Will anyone be able to connect the results of genetic tests to me?

**A:** No. All the information in the COCO90s study is kept separate from your name. No one who works with samples is allowed to know who they came from. This personal information is completely confidential.

**Q:** Would you ever sell my genetic material?

**A:** No, we would never sell these to a commercial company for profit, or any of the information you have given us.

## Why do you want to study my genetic material?

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Although we all have the same genes as each other, there are many small differences in the DNA sequences in our genes which some of us have and others do not. These different versions of our genes can make us more likely or less likely to develop many common diseases, such as allergies, asthma, diabetes or heart disease.

It is not only our genes and DNA that cause disease, we already know that many of our common health problems are partly caused by genes and partly by our environment so we will be looking at your DNA along with other information you give us by questionnaire and at clinics to understand how these diseases occur and how they could be treated in the future.

## How do you get a sample my DNA?

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We can get DNA in several different ways. We can extract DNA and RNA from cells in your blood or saliva. We can also take it from cells in samples of placenta or umbilical cord which can give us the first DNA sample for a child. This extracted DNA and RNA is called your genetic material.

## Where is my DNA kept?

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Your samples, including the main stocks of any genetic material collected, will be stored in the Bristol Bioresource Laboratories, University of Bristol.

A lot of the research using your samples will take place in Bristol but some of your samples, genetic material or the sequence of your genetic material may be made available to researchers working in universities, hospitals or other organisations in the UK or abroad.

We may ask for a small fee from researchers to help cover the costs of storing your samples as well as the costs associated with sending them to other places. We do not charge researchers for the genetic material. We will not sell or make any profit from the samples you donate, and they will only be used in ethically approved research.

## Do I have to give a sample of my DNA or RNA?

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No, at your visits we will discuss all the samples we wish to collect with you, and you will be given the following options for each sample:

- 1) You can decline to give a sample
- 2) You can agree to give the sample but only for a specified set of analysis and then the remaining sample will be disposed of
- 3) You can agree to give a sample for all specified analyses and storage for future **non-genetic** research. This means we will never extract or analyse your genetic material but will do other analyses that are extremely valuable for scientific research.

### *How will our DNA help?*

Children of the 90s has been collecting DNA from participants over a number of years.

- We have DNA from lots of different people with lots of other information about them too.
- We have DNA from different members of the same family.
- We have DNA from 3 generations of some of our families.
- We are able to look at all the different sets of genes everyone has and compare this to their health.
- We can see how genes are inherited.
- We can see which genes may be connected to different diseases.
- We can look at the DNA in a specific gene that we are interested in or we can look at all the genes that a person has.

Our DNA sample collection is one of the unique things about Children of the 90s and what makes us so valuable to researchers.

### *How to contact us*

If you have any questions about this study, please talk to our participation team:

Tel: **0117 331 0010**

Text: **07789 753 722**

Email:

[info@childrenofthe90s.co.uk](mailto:info@childrenofthe90s.co.uk)

Website:

[www.childrenofthe90s.ac.uk](http://www.childrenofthe90s.ac.uk)

4) You can agree to give a sample for all specified analyses and for storage for future research including genetic studies. This means we will extract your genetic material and analyse it.

Providing a sample for genetic research is voluntary and if you choose not to give permission to use your samples to be used in this way, it will not affect your continued participation in Children of the 90s.

## What happens if I change my mind?

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You can change your mind at any time. Write to us and say you don't want us to keep your genetic material and you don't want it used in future research. We will remove the main stocks and destroy them and stop using your genetic sequence. If it has already been used by a researcher, we cannot change this.