CHILD OF THE NEW CENTURY



AGE 11 SURVEY PILOT

WHAT ELSE WOULD WE LIKE YOU AND YOUR CHILD TO DO?

We are inviting you and your child to give a sample of your saliva in order that we can extract a sample of your DNA to be used for research about genes.

WHAT ARE GENES AND DNA?

Genes are the instructions which help determine the growth and development of all living things. For example, genes determine eye-colour. Genes are made up of sections of DNA, which is the language our bodies use to write these instructions. Genes are inherited from our parents and they are the biological way parents pass on traits to their children. Everyone has a slightly different set of genes - so they are like our own personal recipe book.





WHY IS IT IMPORTANT TO STUDY GENES?

Researchers will be able to use the DNA sample to look at whether you and your child have certain types of genes. Studying the relative importance of genes and other factors will help researchers to understand better differences in children's development, health, behaviour, growth and learning. It is important to understand the different influences on children's lives so that policy aimed at improving their lives can be informed by this research evidence.

WHAT RESEARCH WILL BE DONE WITH THE SAMPLES?

Initially researchers will be looking at specific genes which have been shown to influence children's growth and learning. The measurements and assessments that children are doing in the study provide detailed information on their growth and learning. The researchers will use this along side both the information collected about your child's genes, and the other information collected in the survey questionnaires, to help understand what things are most important in influencing growth and learning.

This initial research will be carried out by researchers at the University of Bristol and the University of Cambridge.



WHAT OTHER RESEARCH WILL THE SAMPLES BE USED FOR?

The DNA that is extracted from the saliva samples may be used to look at other genes in the future. Researchers who want to use the DNA to look at a particular gene will have to apply for permission to an independent committee which oversees access to the samples.

WHY DO YOU WANT TO COLLECT DNA FROM PARENTS AS WELL AS CHILDREN?

Parents influence their children in many ways and parents are themselves influenced by their genes. Collecting DNA from parents as well as children will help us to understand genetic influences on parent behaviour which may also have an effect on their children. We would like to collect a saliva sample for DNA from natural (biological) parents who are living with the study child. As children inherit their genes from their parents, we are only collecting saliva samples from parents who are biologically related to the study child.

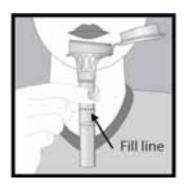
DO WE HAVE TO GIVE SALIVA SAMPLES?

No. Your participation in this part of the study is entirely voluntary and you or your child can choose not to give a saliva sample. This will not affect your participation in the pilot study. The interviewer will ask for your written permission before asking you or your child to give the saliva sample. We will also ask your child for their agreement.



WHAT WILL GIVING A SALIVA SAMPLE INVOLVE?

You and your child will be asked to do the same thing. You will be given a small container and asked to spit your saliva into the container. You should not eat, drink, smoke or chew gum for 30 minutes before giving a saliva sample. About half a teaspoon of saliva is needed. This typically takes about 5 minutes. When finished, the interviewer will place a cap on the container. There is no risk of harm to you or others when giving a saliva sample.





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WHAT WILL HAPPEN TO THE SALIVA SAMPLES?

The interviewer will post the saliva samples to a research laboratory at the University of Bristol. A sample of DNA will be extracted from your saliva. The saliva sample and DNA samples will be stored securely and anonymously. The saliva sample and DNA sample will be stored indefinitely unless you or your child withdraws consent in the future. Small portions of the DNA samples (with an anonymous number) may also be sent to other specialist research laboratories in the UK and elsewhere for analysis. The samples are returned to Bristol.

Your name and address will not be attached to the saliva sample when it is sent to the University of Bristol. The University of Bristol, other research laboratories to which the DNA may be sent and researchers using the DNA will not have access to your name and address.

CHILD OF THE NEW CENTURY

HOW WILL THE DNA SAMPLES BE USED?

The DNA will be used for research purposes only and will be treated in strict confidence in accordance with the Data Protection Act. The DNA samples provided for the pilot will only be used to inform the design of the main survey.

ARE THERE ANY ADDITIONAL RESTRICTIONS ON HOW THE DNA WILL BE USED?

It will not be tested for the HIV (AIDS) virus and will not be available for paternity testing, life insurance, mortgage applications or police records.

WHAT IF I CHANGE MY MIND IN THE FUTURE?

You can withdraw your consent for the storage and ongoing use of your DNA at any time, without giving any reasons, by writing to the Centre for Longitudinal Studies. They will inform the Bristol laboratory and the stocks of your samples will be destroyed. You can also withdraw your consent for the storage and ongoing use of your child's DNA in this way until your child is an adult. When your child is an adult (or earlier if he or she can demonstrate that he or she is old enough to understand), he or she can withdraw permission for the storage and ongoing use of his or her DNA and you will no longer be able to do this on their behalf.

WHO IS PAYING FOR THIS RESEARCH?

The collection of saliva samples, DNA extraction and the initial analysis of growth and learning is being paid for by the Medical Research Council.

WHO HAS APPROVED THIS RESEARCH?

All research which includes the collection of biological samples is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, well being and dignity. This study has been reviewed and approved by one of these committees.

WILL I GET ANY FEEDBACK ON THE RESULTS?

We are not able to send you any individual's specific results as we will only be examining group trends. If you have any concerns about health or development, including any concerns about genetic or inherited diseases, we recommend that you speak to your GP.

HOW CAN I FIND OUT MORE ABOUT THIS PART OF THE STUDY?

If you have any questions you can ask the interviewer or contact one of the Ipsos MORI researchers listed below:

Kirsty Burston

020 7347 3980 kirsty.burston@ipsos.com

Tom Frere-Smith

020 7347 3131 tom.frere-smith@ipsos.com

For further information about the study in general, you can visit the study website: www.childnc.net

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Ipsos MORI

Do I have to do these four things?

interviewer will ask you about them one at a time, and you can say yes or no to each. You can miss out any questions you don't want to answer You don't have to help us with these things if you don't want to. The and stop at any time.



will get anything for doing it?

give you a small present to thank you for taking part. Your family will be given a voucher for £25. The interviewer w

What will happen to the information about me?

It will be used to help decide what happens in the main survey. The answers or measurements to anyone. You do not have to show or tell your name and address. The interviewer will not show or tell your information about you will always be kept completely separate from them will know whose answers they are or whose saliva sample it is. your answers or measurements to anyone, including your parent(s). your name and address on them. This means that no-one who sees The booklet you fill in and the saliva sample that you give will not have



meeting you. Thank you for your help! The interviewer is looking forward to Ipsos MORI

I help with the How can



New Century?

It is an important survey of lots of children. The children time they take part will be when they are 11. have been in the survey since they were born. The next

make things better for children in the future. Scotland, Wales and Northern Ireland today. This will help to It's to find out what it's like to be growing up in England,

We want to test the survey of 11 year olds to make sure it is working. We are asking a small rumber of few different places to help us with this.

what will it be like?

We hope you will find it interesting! Children usually enjoy doing so it is easy for you to understand what you have to do. You the survey. The interviewer will explain everything to you clearly don't need to do anything before hand.

Who is being asked to be in the survey?

won't ask your teacher if you don't want us to. You, your parent(s) (that you live with) and your teacher. We

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on your own. You can ask the interviewer to help you if you find it difficult to do it on your own. The interviewer will give you a booklet of questions to fill in

what you think about things and growing up. things include your family and friends, school, the things The questions are about lots of different things. These you do outside school, the area you live in, how you feel

how I am growing. Be measured to find out (2)15 minutes

The interviewer will find out how tall you are using a ruler, measurements if you want. tape measure. The interviewer will give you a copy of your is using special scales, and the size of your waist using a how much you weigh and what your body fat percentage

What if I have questions

everything before you start. and make sure you understand will ask you if you have any questions The interviewer will explain everything to you when they come to see you. They



to do four things:





Give a saliva sample so they can learn more about how I grow and think.

and are like recipes for what people are like. The way children grow and think is decided in part by their genes. Saliva contains something called 'genes'. Genes are part of you saliva, the interviewer will ask you to spit into a small plastic tube Saliva is the watery stuff you have in your mouth. To collect your

out how I thunk.

We'd like you to do some activities to find out how you think

also ask you to do some activities on a computer.

Do some activities to find (>)

30 minutes







