

G1 biological sample collection participant information sheets and consent forms post HT Act

Please note

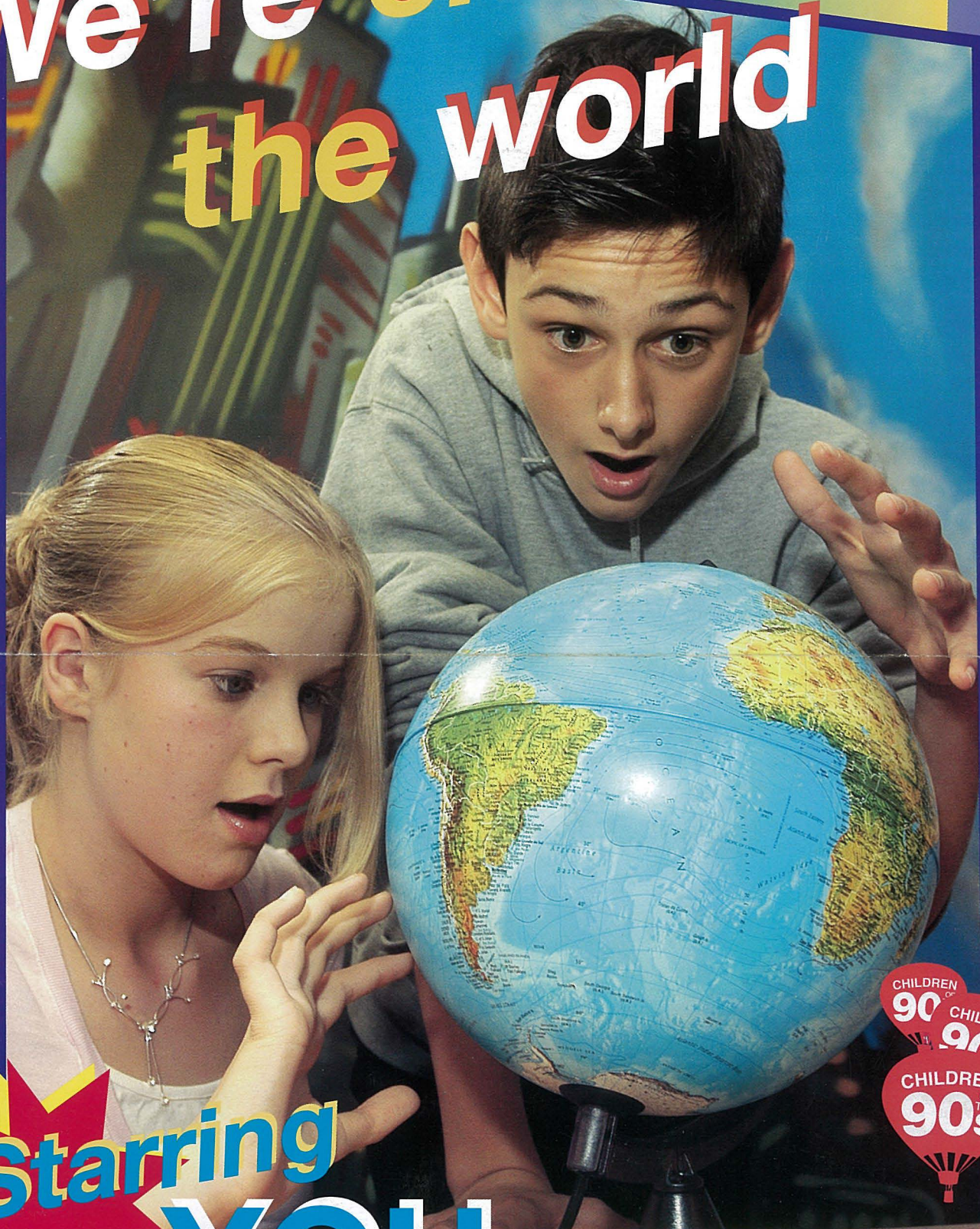
- These samples were collected after the commencement of the HT Act (1st Sept 2006)
- Other versions of the documentation provided may have been used during sample collection
- The request for donation of specific sample types may have changed throughout the course of the collection timepoint

Table of samples collected for G1 post HTAct and their corresponding consent form and participant information sheet

cohort	collection	sample collection dates	sample type	non HTA relevant material	HTA relevant material existing holdings	HTA relevant material post HTAct	consent requested from G1-participant GO-parent/guardian	copy of PIS provided	copy of consent form provided
G1	Teen focus 2 *	2005-03 to 2006-09	whole blood, blood derivatives, cell line, DNA	Y	Y		G1 and GO	1. We're changing the world (pg. 1)	1. TeenFocus2 Blood consent Child (pg. 5) 2. TeenFocus2 Cell Line Consent (pg. 6)
G1	Date study *	2005-05 to 2007-06	urine		Y	Y	G1 and GO	1. Date Study (pg. 7)	1. Date Study Information Sheet (pg. 9)
G1	Teen focus 3	2006-10 to 2008-11	whole blood, blood derivatives, urine, hair, cell line, DNA	Y		Y	G1 and GO	1. TeenFocus3 Info 1 Fasting Blood (pg. 10) 2. TeenFocus3 Info 2 Fasting Blood (pg. 11) 3. TeenFocus 3 Info Hair (pg. 14) 4. TeenFocus 3 Info Urine (pg. 15)	1. TeenFocus3 Consent Fasting Blood (pg. 12) 2. TeenFocus3 Consent Young Person DNA and Cell Lines (pg.13) 3. TeenFocus3 Combined consents (pg. 16)
G1	Focus at age 17	2008-12 to 2011-08	whole blood, blood derivatives, urine, hair, cell line, DNA	Y		Y	G1 and GO	1. F17+ Participant Information Booklet (pg. 17) 2. TF4 DNA, Genes and Cell-lines Information Sheet (pg. 43)	1. Focus 17 Combined Consent (pg. 39) 2. TF4 ALSPAC Urine Consent (pg. 41) 3. Focus 17 DNA and Cell Line Consent (pg. 45)
G1	Breast tissue composition study	2012-06 to 2015-01	blood derivatives, urine	Y		Y	G1	1. Breast Tissue Composition in Young Women. Information sheet (pg. 46)	1. Breast Tissue Composition in Young Women. Consent Form (pg. 50)
G1	Focus at age 24	2015-06 to 2017-10	whole blood, blood derivatives, urine, , cell line, DNA, RNA	Y		Y	G1	1. Focus@24+ Information for you (pg. 51)	1. Focus@24+ Consent Form (pg. 68)
G1	Understanding asthma study	2017-06 to 2018-10	blood derivatives, nasal lavage and derivatives, sputum and derivatives, DNA	Y		Y	G1	1. Understanding Asthma study. Participant Information Sheet (pg. 71)	1. Understanding Asthma study Visit 1 consent form (pg. 79)
G1	Understanding eczema study	2018-03 to 2020-11	blood derivatives, skin biopsy, skin microbiome, DNA, RNA, PBMC	Y		Y	G1	1. Understanding eczema. Information sheet (pg. 81)	1. Understanding eczema consent form (pg. 87)
G1	UK coronavirus immunology consortium	2020-11 to 2021-07	blood derivatives, urine, saliva	Y		Y	G1	1. UK CIC Participant Information (pg. 90)	1. UK CIC Consent form (pg. 95)

NB: Page numbers in table are those labelled as 'G1 participant sample documentation post HTAct page' in document. * The collection includes samples donated pre and post HT Act.

We're changing the world



CHILDREN OF THE 90s
CHILDREN OF THE 90s
CHILDREN OF THE 90s

Starring
YOU

and a cast of thousands....

at **STANBOLUS**

Reception area:
Battle the aliens on our new space invaders machine.

Day in the life

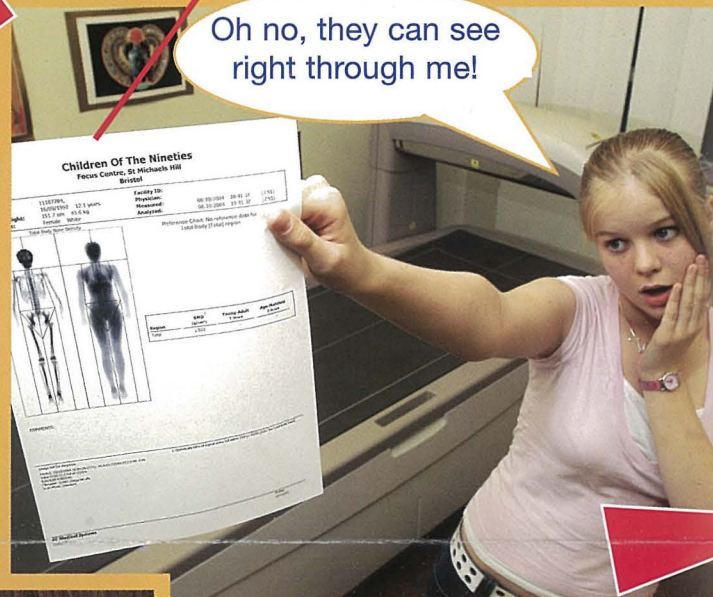
As soon as they arrive, Reuben and Kez can see that Focus is going to be fun



Hmmm.... it's looking good!!!

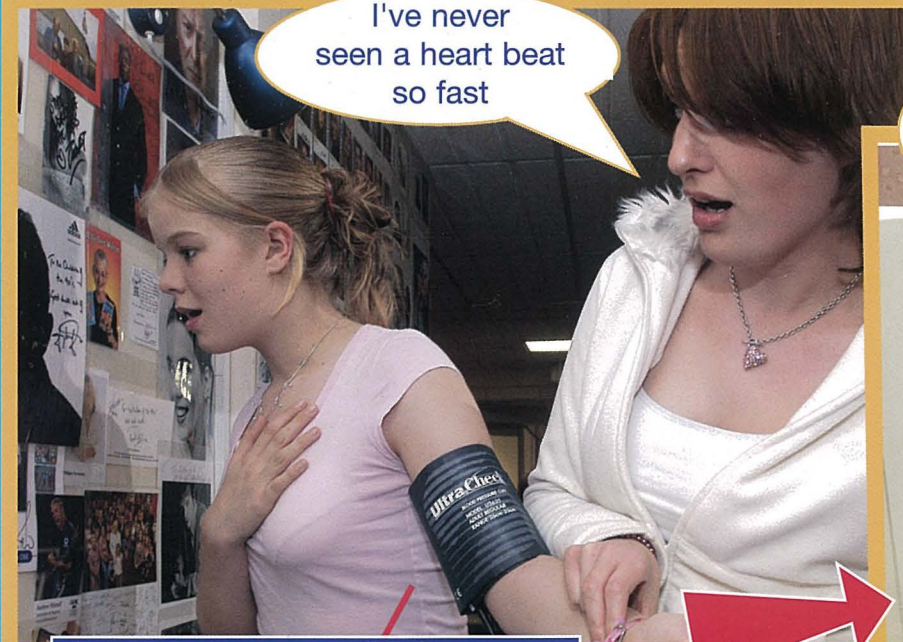
Measuring: You will be able to see how your skeleton is. Also, for the first time we will also be looking at how you are

Kez sees herself in a totally new way



Oh no, they can see right through me!

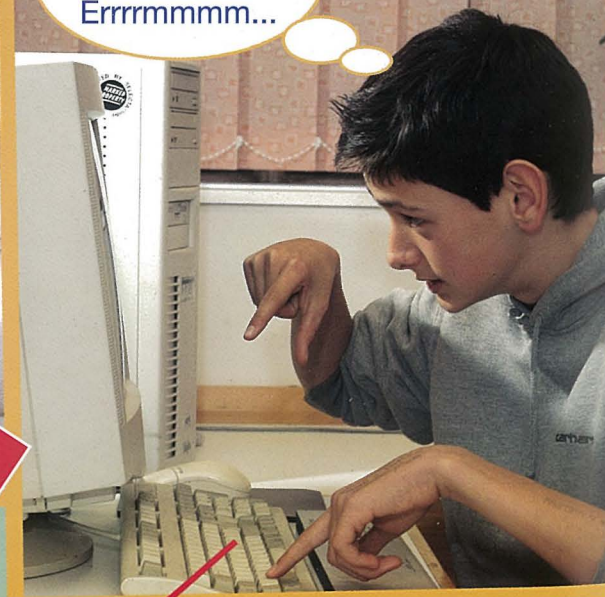
I've never seen a heart beat so fast



but Kez has spotted her heart-throb on the Wall of Fame

It asks, "Are you decisive?" Errrrrrmmmm...

Reuben is determined to beat the computer



Blood pressure:
We'd like to check your blood pressure to see if it is changing as you get older.

Computer sessions:
We will be asking about your life and about your friends on the computer. There are some games to play too.

Diet:
How has what you eat since you were 10+? The forms you fill in help us to do a survey of 13-14 year olds' diets

of TEENFOCUS2

Fitness:
We want to see how fit you are and whether this has changed since you were 9+.

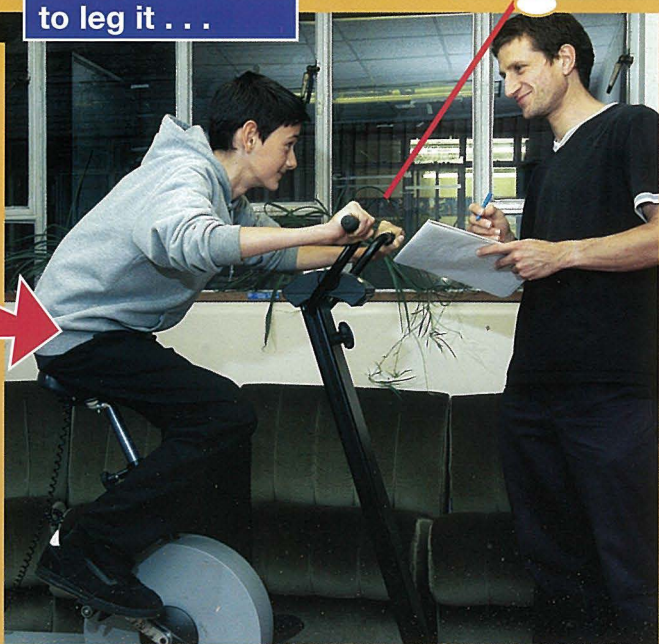
is developing again with our special low dose scanner.
flexible some of your joints are.

Then things get even weirder . . .

Are we going round the bend?

Reuben decides to leg it . . .

This guy should go in for the Olympics!

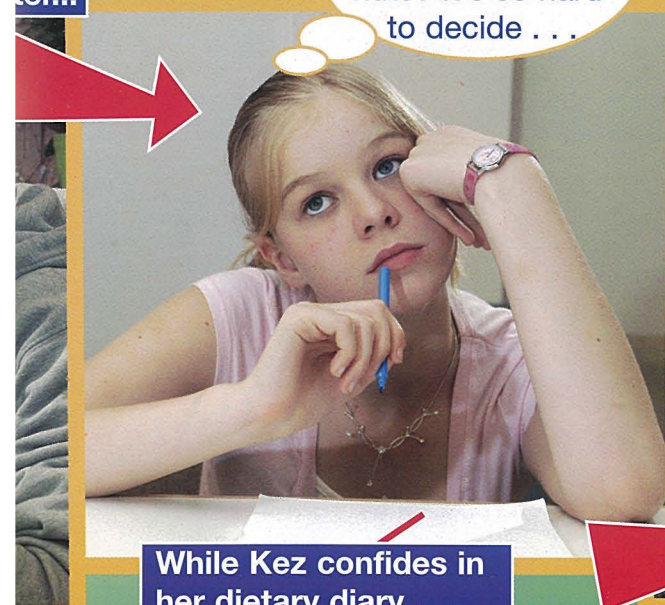


I've had enough excitement for one day

Carrot stick or 6-pack of doughnuts? It's so hard to decide . . .

Better not over-do it . . .

ned
ter...



While Kez confides in her dietary diary . . .

. . . and they both test out their activity monitors

Activity monitors:

The monitors that you wore at 11+ are producing excellent information in relation to diet, blood pressure, height, weight and so on. We need to see how these things change as you get older.

NOW! Turn the page to find out more...

and drink changed dietary diaries over what we like today.



WHAT YOU CAN EXPECT AT...

TeenFocus2



You may feel that lots of things are changing in your life - at school, with your friendships, tastes and attitudes, abilities and interests. We want to monitor those changes and describe, in scientific papers, what it means to be growing towards adulthood in the first decade of the 21st Century.

That's why your visit and the information you give are so important. It's also why some of the

measures and questions are apparently the same as before. The results may be very different this time, because you are older.

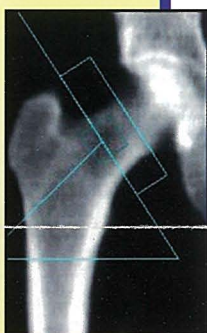
You can say no, or stop if there is anything you don't want to do or answer. All the information you give us is stored anonymously. We are sorry that we can't feed back to you all your own results, but we can give you height, weight, and blood pressure measurements.

You're changing the world!

Because of you and all the children of the 90s, people across the globe can look forward to happier and healthier lives. So, as a symbol, we're creating a picture of the world, made up of your faces which will become a poster for the Focus Centre. We'll be sure to have a magnifying glass on hand too so that you can spot your friends.

Measuring

Are you happy for us to measure your height, weight, arm and hip circumferences and the straightness of your back? If so please wear clothes you're happy to be measured in. We'll be doing an additional scan of one hip (see picture). This is something that is usually done when people have a scan of their whole body.



● To contact **TeenFocus2**

call: 0117-928 8266

Interview and Computer session

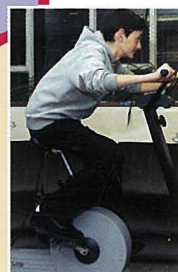
We want to see how things in your life are changing as you get older. We are interested in the moods and feelings that you have and what sort of person you think you are.

Blood pressure and sample

Would you like to give blood and saliva samples this time? We know we ask you frequently but these samples are so valuable. They answer so many questions especially about things like hormones and antibodies to infection which change over time. Like everything at the visit it's entirely voluntary so you can always say no.

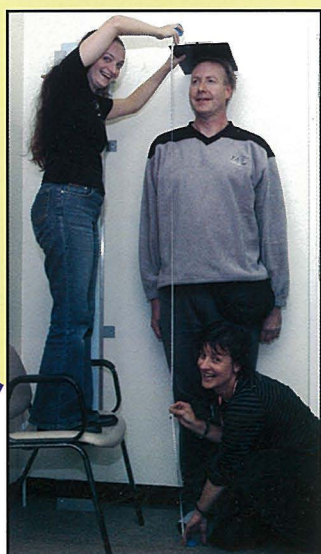
Fitness

To test your fitness, we may ask you to do a basketball task instead of cycling, (pictured).



Parents

Don't feel left out! You often tell us that you want to be involved and we plan to ask if you would be willing to give us a blood sample and if time to have your height, weight and blood pressure measured. As always at these visits everything is voluntary and if you can help us with these things it is a bonus. As you can see from the picture here we had a bit of fun 'sizing up' a 6ft 5in study dad!



... and if you have time to spare at TeenFocus2 there's the Exploratory to explore again - you may find some different things there this time!

◆ Log on to your Children of the 90s website for the latest competitions, games and news www.alpac.bris.ac.uk/discovery



PARENTAL CONSENT FOR EMLA

Has your child ever had a bad reaction to local anaesthetics? Y/N

Has your child recently used or been given a local anaesthetic? Y/N

Is your child taking any medication containing sulphonamides? Y/N

.....

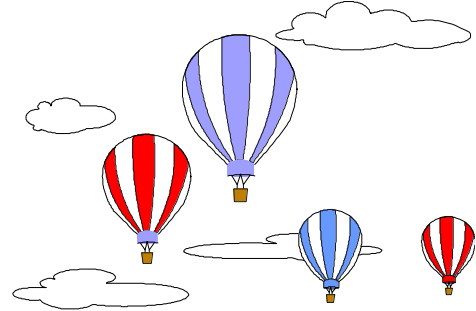
Is your child anaemic? Y/N

Does your child suffer from any clotting or bleeding disorders ? Y/N

Signed.....

Date.....

CHILDREN OF THE 90s



TeenFocus2

24 Tyndall Avenue
Bristol BS8 1TQ
(correspondence only)

Tel: 0117 928 8266 There is an answer phone on this line.
e-mail: focus-admin@bristol.ac.uk

Permission to use blood samples

Once the sample has been taken, you will be informed within a few days if it shows that your child may have a low haemoglobin (below 9g/dl). After that analysis the name will be taken off the blood samples and they will be stored for future analyses. The blood samples will have no names attached to them. Results will be used for statistical purposes only and not linked to named children.

PARENTAL CONSENT

The purposes and possible risks in my child having blood taken have been explained to me. I understand that donated blood will be considered a gift but I will have the right to withdraw permission for analysis.

I agree to my son/daughter having blood samples taken for analyses for the 'Children of the 90s' study:

I am his/her parent (or guardian) or have parent's permission to give consent.

Signed:

Date:

Name (PLEASE PRINT).....
(Parent/Guardian or representative)

STUDY CHILD CONSENT

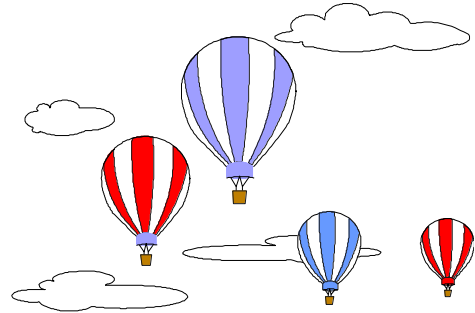
I am the young person participating in the study.

Signed: (Study child)

Name (PLEASE PRINT)..... (Study child)

The University of Bristol holds legal liability insurance in the event that any participant is injured due to any negligence on the part of the University.

CHILDREN OF THE 90s



TeenFocus2

24 Tyndall Avenue
Bristol BS8 1TQ
(correspondence only)

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e-mail: focus-admin@bristol.ac.uk

Permission to use blood sample for cell lines

After processing the name will be taken off the blood samples. The cell lines and DNA samples will be stored with no names attached to them. Results will be used for statistical purposes only and not linked to named children.

PARENTAL CONSENT

The purposes and possible risks in having blood taken have been explained to me. I understand that donated blood will be considered a gift but I will have the right to withdraw permission for analysis.

I agree to my son/daughter having the following blood samples taken for analyses for the 'Children of the 90s' study:

- 1. A sample for cell lines ('immortalised' DNA) }
- 2. A sample for DNA only } *delete as applicable*

I am his/her parent (or guardian) or have parent's permission to give consent.

Signed: Date:

Name (PLEASE PRINT).....
(Parent/Guardian or representative)

STUDY CHILD CONSENT

I am the young person participating in the study.

Signed: (Study child)

Name (PLEASE PRINT)..... (Study child)

The University of Bristol holds legal liability insurance in the event that any participant is injured due to any negligence on the part of the University.

DATE STUDY

24 Tyndall Avenue

Bristol BS8 1TQ

(correspondence only)

Tel: 0117 3311731

e-mail: louise.glynn@bristol.ac.uk



INFORMATION SHEET

Why are we doing the DATE study?

When we do research it is very important to make sure that the measurements we make are really accurate. We actually need to be able to prove that they are! To do that we need some volunteer study members who will do some of the measures again for us to compare our results with.

Why are we measuring diet and activity again?

In this study we are looking at diet and activity so we need you to wear an activity monitor for 3 days and record what you eat and drink for the same 3 days. We will ask you to do this for 3 different seasons; each season is 3 months apart. We have previously asked you to fill in a food diary, and wear an activity monitor, but not at the same time. Diet and activity go together so in this study we want to measure them at the same time.

In order for your body to work it needs to get energy from food and drink which it uses up during the day doing various activities. Your food and drink diary will help us work out how much energy you get from your food and drink every day and wearing the activity monitor will help us to work out how much energy you have used that day. Measuring them at the same time will allow us to assess if there is a relationship between the two.

Why are we measuring diet and activity in the various seasons?

What you eat and how active you are might vary from season to season. They may also vary between school time and holidays. In this study as well as checking that our measurements for diet and activity are accurate, we are investigating if the season of the year affects what you eat and your activity levels.

Why are we collecting urine samples?

In addition to measuring diet and activity we would also like you to collect 3 overnight urine samples each season. This is because by-products of the food you eat are present in your urine; these natural chemicals can give us more information about your diet that we cannot find out from your food records alone. Therefore it would be really useful if you could collect samples of your urine.

What will happen if I agree to take part?

If you decide to take part in the study, you will be contacted by phone to arrange a time when one of the study team can come to your home. One of the research team will bring the DATE study pack, to your home and talk to you and your parents/guardians about the study and ask for consent. The pack contains

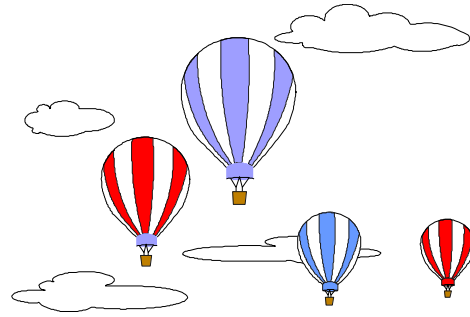
- A food diary and questionnaire
- A physical activity kit
- A urine kit

Each season you will be asked to choose 3 days on which to record what you eat and drink in the food diary, preferably two weekdays and one weekend day. For these three days we shall also ask you to wear the activity monitor called an actigraph, and collect overnight urine samples on those three days. The actigraph is a little plastic box that you wear around your waist; it measures your physical activity by recording all of your movements. You will be asked to send your urine samples back to us in the post, in special tubes and envelopes provided by us. After you have completed the food diary one of the researchers will visit you at home and check through the diary with you and your parent/guardian. The researcher will measure your height and weight. They will leave you a pack (without the actigraph which will be posted to you) for the next season. We will telephone in three months time to remind you to do the various measures, and to arrange a suitable time for another home visit. This is when we will post the actigraph out to you.

There will be no risk or benefit to you from taking part in this study. All of the results will be kept confidential. This study has received ethical approval.

You can stop the study at any time if you wish. We will bring your voucher when we visit after each season.

Thanks again for your help.



Fasting bloods

Q and A

TeenFocus3

24 Tyndall Avenue
Bristol BS8 1TQ
(correspondence only)
Tel: 0117 928 8900 (answer phone)
e-mail: focus-admin@bristol.ac.uk

What are fasting bloods?

- samples of blood taken at the end of a period of fasting. Ideally this is after fasting overnight (from 11pm) and before you have breakfast. (It can also be in the afternoon IF you have not eaten since breakfast.)

Why do you need them?

There are many substances carried in your bloodstream which have an important influence on your future health and development. Some of these can only be measured in fasting blood. These include things like insulin, glucose and several hormones, which are crucial measures for the study.

May I have anything during the fast?

Morning visits:

You can't have any food or sugar-containing drinks such as fruit juices, sodas (fizzy drinks), tea or coffee with sugar, after waking up on the morning of your Focus visit until after the sample has been taken.

You can have sips of water.

(If an afternoon visit is necessary for you:

You may have a light breakfast BEFORE 8am but please do not have anything except sips of water after that.)

Will I have anaesthetic cream?

We will send this to you in advance with instructions if you would like to use it.

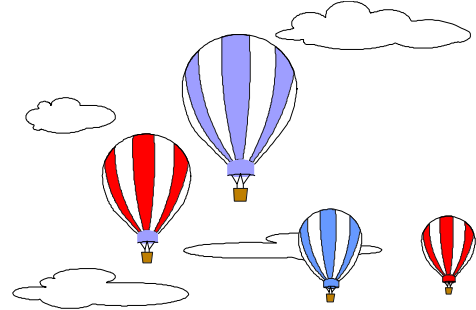
What happens if I forget?

Make a note of what you had to eat or drink on the record form and call us on 0117 928 8900 and ask if you need to change your appointment. If not, bring the note of what you had with you.

What happens after the sample is taken?

We give you a light breakfast - fruit juice, cereals, toast, croissants, yoghurt, fruit, tea or coffee (or a light lunch - fruit juice, cheese, biscuits, cereal bars, fruit, crisps).

Let us know if you have any special dietary needs. You are welcome to bring your own food with you if you prefer.



Fasting bloods

- more information

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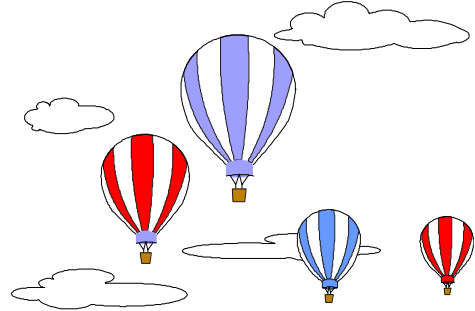
Why are we collecting fasting blood samples at TeenFocus3?

In studies like Children of the 90s many measurements are taken of substances in the blood which may influence future health and development. These include some that are influenced by diet such as cholesterol, hormones such as testosterone or oestrogen, and antibodies to infections.

We have collected blood at previous Focus visits for measurement of various things on some or all of you. These have been non-fasting samples. They are fine for substances which don't change much when you eat something. For example, and perhaps surprisingly, the level of the best known fat, or lipid, in the blood – total cholesterol – doesn't depend on what you have eaten recently. After a full English breakfast of eggs and bacon no real change can be seen. The level actually reflects your diet in the long-term - the effects of weeks or months of your dietary intake.

However the levels of some other substances, such as blood glucose or another blood fat, triglyceride, change a lot and very quickly when you eat. The levels will reflect how much and how recently a person has eaten.

It is thought that measuring levels of substances such as these in fasting blood gives more useful information. **That is why we are asking that you do not eat from 11p.m. the night before a morning visit, or for at least 4 hours if you have to come in the afternoon.** This will allow accurate measurements of those substances that do change in response to diet as well as those that don't. It will also allow us to assess how these measurements relate to patterns of growth, development, diet, exercise, etc and how they might be able to predict future health and development.



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e-mail: focus-admin@bristol.ac.uk

Permission to use fasting blood samples

Once the sample has been taken, you will be informed within a few days if it shows that your teenager may have a low haemoglobin (below 9g/dl). After that analysis the name will be taken off the blood samples and they will be stored for future analyses. The blood samples will have no names attached to them. Results will be used for statistical purposes only and not linked to named young people.

STUDY TEENAGER CONSENT

The purposes and possible risks in having blood taken have been explained to me. I understand that donated blood will be considered a gift but I will have the right to withdraw permission for analysis.

I agree to my having blood samples taken for analyses for the 'Children of the 90s' study:

I am the young person participating in the study.

Signed: (Study teenager)

Name (PLEASE PRINT)..... (Study teenager)

PARENTAL CONSENT

I am his/her parent (or guardian) or have parent's permission to give consent.

Signed: Date:

Name (PLEASE PRINT).....
(Parent/Guardian or representative)

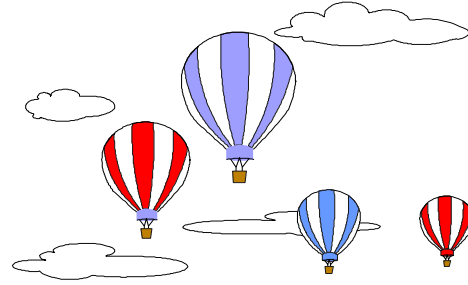
Parent/guardian permission obtained by phone and copy attached not required (age 16)

The University of Bristol holds legal liability insurance in the event that any participant is injured due to any negligence on the part of the University.

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Permission to use blood sample for cell lines

After processing the name will be taken off the blood samples. The cell lines and DNA samples will be stored with no names attached to them. Results will be used for statistical purposes only and not linked to named people.

STUDY TEENAGER CONSENT

The purposes and possible risks in having blood taken have been explained to me. I understand that donated blood will be considered a gift but I will have the right to withdraw permission for analysis.

- 1. A sample for cell lines ('immortalised' DNA) }
- 2. A sample for DNA only } *delete as applicable*

I understand that the main stocks of DNA and/or cell lines will be stored in Bristol, but that the DNA/cell lines (with an anonymous number only), or information about the sequence of my DNA, may be sent to specialist research laboratories in the UK and abroad for analyses and the results returned to Children of the 90s. Researchers at these laboratories have no access to personal information about study participants. I agree that the information about my genes can be analysed together with information about my health, disease and life style factors in order to undertake research into biological or genetic factors affecting the risk of developing a range of common medical conditions. I understand that any such analyses will only be undertaken on data from which all personal information has been removed and replaced with an anonymous code.

I am the young person participating in the study.

Signed: (Study teenager)

Name (PLEASE PRINT)..... (Study teenager)

PARENTAL CONSENT

I agree to my son/daughter having the above blood samples taken for analyses for the 'Children of the 90s' study:

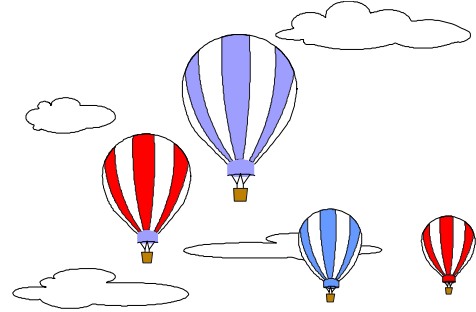
I am his/her parent (or guardian) or have parent's permission to give consent.

Signed: Date:

Name (PLEASE PRINT).....
(Parent/Guardian or representative)

Parent/guardian permission obtained by phone and copy attached not required (age 16)

Hair samples



Q and A

TeenFocus3

24 Tyndall Avenue
Bristol BS8 1TQ
(correspondence only)
Tel: 0117 928 8900 (answer phone)
focus-admin@bristol.ac.uk

Why do you need hair samples?

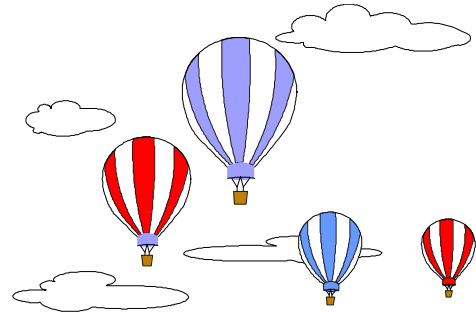
A hair sample can tell us about substances that you may have been exposed to in the past. Hair carries traces of substances from food, drink, drugs or the air you breathe. Information from these samples can be analysed along with information from questionnaires that all the study participants have filled in. This will enable us to show whether any of these substances causes harm and if so what is a safe level.

What do I have to do if I agree to give hair samples?

We would like to cut a sample from close to your scalp, keeping the hairs together in a bundle. You can decide where we do it, such as at the back just above the hairline where it will not show. The little bundle of hair needs to be about 2mm across ideally at least 3cm long. If it is much shorter it needs to be a bit thicker to provide enough hair for analysis.

Will you link information from the samples to me?

All samples and other information from you have a number put on them and your personal details removed as soon as we receive them. We can then link information about the same person together by these numbers but we do not link it to any individual – or to you - just to a number.



Urine samples

Q and A

TeenFocus3

24 Tyndall Avenue
Bristol BS8 1TQ
(correspondence only)
Tel: 0117 928 8900 (answer phone)
focus-admin@bristol.ac.uk

Why do you need urine samples?

The kidneys filter your blood, remove substances you don't need and excrete them in the urine. Therefore urine can tell us about things that you may have been exposed to. It can also give a measure of your body's responses to its environment. For instance, it can show how your body reacts to things like viruses, pollen or certain foods because of the substances released by the tissues which can be measured in the urine.

What do I have to do?

Take the jug and container you will be given by the Receptionist and take them into the toilet for people with disabilities. We would like a 'mid-stream' sample of urine so -

- pass a little as you would normally do, then stop
- hold the jug so as to catch a sample of urine
- remove the jug and pass the rest of the urine as normal
- pour a sample of the urine from the jug into the container
- pour the remainder down the loo
- put the container into the box labelled 'Containers'
- rinse the jug and put it into the box labelled 'Jugs'
- wash your hands

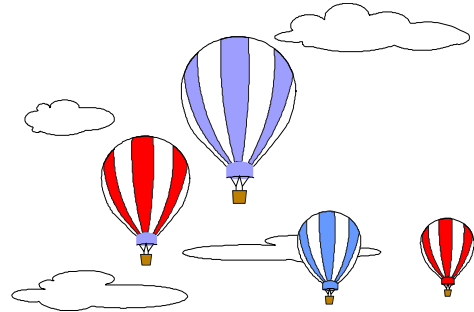
Will you link information from the samples to me?

All samples and other information from you have a number put on them and your personal details removed as soon as we receive them. We can then link information about the same person together but we do not link it to any individual – or to you - just to a number.

What will you do with my sample?

We will store your sample by freezing it at -80°C in special labelled tubes to preserve all the chemicals in it. Levels of these chemicals will be measured later and related to health and development. By linking these results anonymously to other information we have on you the researchers will be able to answer important questions that will improve the health of future generations.

Consents



TeenFocus3

24 Tyndall Avenue
 Bristol BS8 1TQ
 (correspondence only)
 Tel: 0117 928 8900 (answer phone)
 e-mail: focus-admin@bristol.ac.uk

I have read and understood the information sheets on the following tests and understand what they will involve. I understand that all tests are completely voluntary. The purposes and possible risks have been explained to me and I have been given an opportunity to ask questions. I know that the tests will end if I ask for them to stop.

I consent to those tests which I have marked with a tick and initialled. I am happy that the data are stored with individual ID but no name or personal details attached, for storage and use by Children of the 90s' researchers and collaborators. I agree to do the following:

- 1. the lung function tests *initialled:*
- 2. be given Ventolin
- 3. have a face shape image taken
- 4. the cycling task
- 5. whole body DXA scan
- 6. pQCT scan of lower leg

The following samples are to be considered a gift but I will have the right to withdraw permission for analysis.

- 7. give a hair sample
- 8. give a urine sample

STUDY TEENAGER CONSENT

Signed:(Study teenager) Date:

Name (PLEASE PRINT)..... (Study teenager)

PARENTAL CONSENT

I am his/her parent/guardian, or have parent's permission to give consent and agree to him/her participating in the above measures.

Signed: Date:

Name (PLEASE PRINT).....(Parent or Guardian)

Parent/guardian permission *obtained by phone and copy attached* *not required (16 or over)*

**ALSPAC**

Avon Longitudinal Study of Parents and Children

Oakfield House
Oakfield Grove
Clifton
Bristol BS8 2BN
Tel: 0117 3310011
focus-admin@bristol.ac.uk

www.alspac.bris.ac.uk

Focus 17+



Participant Information Booklet

This booklet provides information on measures that are being done at Focus 17. Please take time to read the information, which will help you decide whether or not you wish to complete any of them.

Please ask us if there is anything that is not clear.

You can:

Email: focus-admin@bristol.ac.uk

Phone: 0117 3310011

Text: 07789753722

If you require this information in an alternative format e.g. large print then please contact us.

What will happen on the day?

Focus17 takes place at the Children of the 90s Centre where you can help with important health research

- The visit takes about **half a day**; bring a friend if you like!
- We can arrange for a **free taxi** to bring you to the Children of the 90s centre, or there's free parking if you drive



- When you arrive you **meet one of our team**,
- At the start of the visit we will **explain what's involved** and give you the chance to ask any questions



- You can have **breakfast or lunch** in our café
- You go from **session to session**; each one varies in time, but can take between 20 and 40 minutes. Each one will be explained in turn and you only do the sessions you want



- At the end of the visit, you get a **£20 voucher**
- You also get a **BIG THANK YOU** from us for giving so much of your time to this research

- We can arrange for a **free taxi to take you home**
- There are **extra measures** called 'GRACE' 'ELBA' and 'Arteries'; these look at your heart, arteries and blood pressure. If you want to do them but haven't time to do them on the day then you can arrange another visit

Details of the measures involved are in the following pages

The DXA Scan

We would like to do a scan from the top of your head to the soles of your feet as well as a more detailed scan of your hip.

Why?

There are two reasons why such a scan is going to be useful for the future.

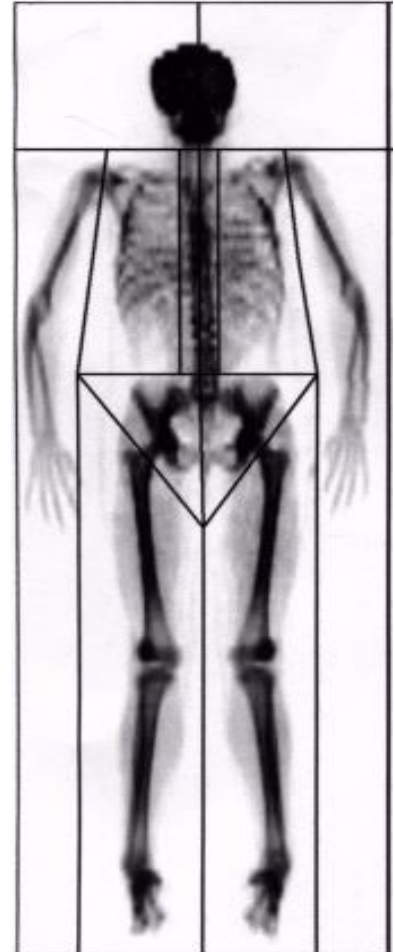
We spend a lot of time weighing and measuring you but this doesn't tell us everything. For example one person can be just the same height and weight as another, but one may have big bones and the other have a lot of muscle. We will eventually be able to work out these differences from the scans and other information collected.

One question that people ask more and more concerns the strength of our bones. We know that for adults this depends partly on our genes and partly on what we eat and how active we are. What we don't know is what is important in bone growth and development. We know that most people have a completely different diet now compared to 20 years ago. Many eat less and they eat differently. Many walk less and exercise less. This may be storing up problems for the future – and the best way to find out is to look and see what is happening now and see if there are causes of concern and ways in which we can prevent problems in the future.

The hip scan gives more information about bone structure and the likelihood of your bones breaking when you are older.

Is it safe?

Although this machine uses X-rays, the level of radiation used is minute. For example, the X-ray dose of 5 microsieverts is less than the average daily natural radiation dose we get from the soil, air and buildings around us, and is considered to carry no measurable risk at all. We can provide more detailed information if you ask us.

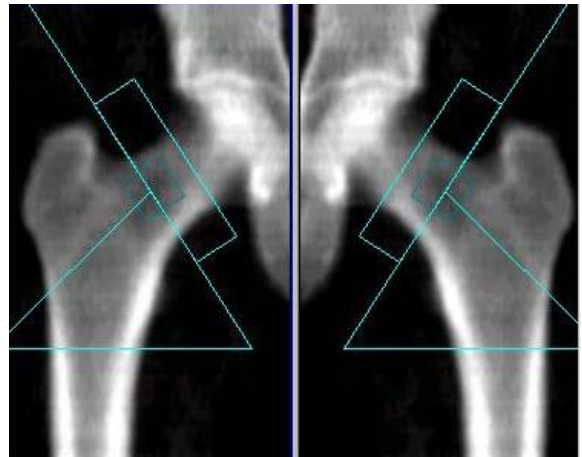


How does it work?

We use a machine called a Lunar Prodigy narrow fan beam absorptiometer. In spite of such a complex name, the machine is very simple.

You will be asked to lie on a bench. It's most important that your clothes don't have any metal fastenings. Watches, earrings and other metal objects should also be removed if possible, since these can interfere with the result. You will be asked to lie very still – for just 3 or 4 minutes.

The machine's arm will then slowly pass over you twice; the first time is in order to scan the whole skeleton; the second scan is intended to provide more detailed information of the structure of your hip, and is the site generally analysed in teenagers as well as adults on this type of scanner.



The Hip Scan

The second scan is carried out in a very similar way to the first, with the exception that the foot is positioned against a rest in order to rotate the hip at a 45 degree angle.

Once the scan is over, we will give you two pictures: one of your whole skeleton, and a more close-up picture of your hip.

The Fractures Questionnaire

You will be asked whether you have broken a bone since you were 12. If you have, we would like your permission for one of our researchers to contact you for more details. We will also ask for permission to look at your X-rays.

We want to investigate the different causes of fractures to see if they are linked to bone strength.

**Do you want to talk about these measures with someone?
Please talk to your parents/guardians or perhaps a teacher or GP. If you prefer, they can get in touch with us on your behalf.**

Fasting Bloods

Why are you collecting blood?

Many substances that may influence health and development can only be measured accurately in blood. These include some related to diet such as cholesterol, hormones such as testosterone or oestrogen, antibodies to infections and some vitamins. Most of these things change over time, which is why we ask you to give a blood sample at different Focus visits. We are also collecting blood to use to make cell lines and for extraction of DNA – see the next section for information.

What are you looking at in the blood this time?

We are looking at blood lipids (fats), glucose/insulin, haemoglobin and cotinine (a measure of exposure to nicotine by smoking, including passive smoking). We would also like to store some blood for future use.

Why fasting bloods?

The levels of some substances, such as blood glucose, insulin, or a blood lipid triglyceride, change a lot and very quickly when you eat. The levels will reflect how much and how recently a person has eaten.

Measuring these levels can only be done accurately in fasting blood. We can use fasting blood to measure other substances not influenced by diet too.

Is it safe?

The small amount of blood we are taking will not affect your health. We will check before taking the sample that you are able to do so safely.

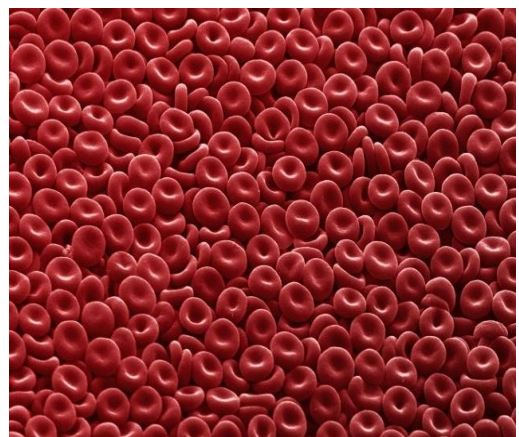
There is a slight risk that you will feel faint during or after giving the sample. Our staff are trained how to look after you if this happens.

You may have a small bruise where the blood was taken. This will clear within a couple of days.

What happens after the sample is taken?

We give you breakfast or lunch in our café!

Let us know if you have any special dietary needs. You are welcome to bring your own food with you if you prefer.



DNA, Genes, and CELL LINES

Our genes are important in making us more or less likely to develop many common diseases. We all have a slightly different set of genes in our bodies. To help us look at these differences and understand the causes of diseases, we have been asking the young people coming to Focus visits to provide a small blood sample we can use to purify DNA for genetic studies. We are also able to treat the sample to produce a cell line which can provide a never-ending supply of DNA. These cells can also be studied to provide a more detailed description of how some parts of the body work.



What are genes?

Genes are the instructions, which determine growth and development of all living organisms.

What is DNA?

DNA is the chemical language in which genes are written.

Why do you want to study my DNA?

Although we all have essentially the same genes as each other, there are many small differences, which some of us have and others do not. These different versions of our genes make us more likely or less likely to develop many common diseases, such as allergies (like asthma), or diabetes or heart disease. We want to discover which versions of particular genes increase the risk of these diseases and which versions protect us.

Is it just genes that cause disease?

No. We already know that many of our common health problems are partly caused by genes and partly by our environments.

How will my DNA help?

By discovering the way in which genes and the environment cause common diseases we will be able to discover what makes people more likely to develop diseases like asthma or diabetes. We can then develop better ways of preventing or treating them.

Why do you need more DNA?

We each have about 30,000 genes. With your permission, we want to study many of these genes, but the DNA we have collected so far will run out before we can complete this work. We would like to collect a blood sample from you and treat the cells from the blood so that they can be stored indefinitely as 'immortalised' cell lines. These cells can be used to make more DNA whenever it is needed.

What are *immortalised* cell lines?

Skin, muscle, bones, blood, and all the other parts of our body, are made up of millions of cells. Each cell has a copy of all our genes. If we take cells from our bodies we can only keep them alive for a limited time. However if cells are treated with a special safe virus they can be kept alive indefinitely - they become *immortalised*.



Do *immortalised* cell lines have other uses?

Yes they do. Cells from cell lines retain some of the basic features, as well as the DNA, of the people they came from. We can look for changes over time in the way the cells behave and for certain markers. For example, one study found that cell lines from people with raised blood pressure grow faster than those from people with normal blood pressure. Studying cells in this way may provide important stepping-stones that will help bridge the gap between genes and the whole person and improve our understanding of how the two are linked.



Where are my DNA and/or cell lines kept?

The main stocks of DNA and cell lines are stored here in Bristol. They will be kept indefinitely. Small portions of the samples (with an anonymous number) are also sent to specialist research laboratories in the UK and abroad for analysis, and the results are returned to us. Outside researchers who work with

Children of the 90's data or samples are bound by a strict code of conduct and have no access to information that would identify study participants.

Would you ever sell my DNA or cell lines?

No, we would never sell these, or any of the information you have given us.

If the 'Children of the 90's' study makes cell lines from my blood, can I be sure they will not be used for cloning?

Yes, you can be sure. The use of human tissues, DNA, and cell lines is strictly controlled. Charities and government organisations which give money for research, Bristol University, and the Children of the 90s study ethics committee, which includes parents of study participants, would not allow human cloning.

If I change my mind later and don't want you to keep my DNA or cells, what should I do?

You can change your mind at any time. Write to us and say you don't want us to keep your DNA or cells. We will remove the main stocks and destroy them.

Hair Sample

Why do you need hair samples?

A hair sample can tell us about substances that you may have been exposed to in the past. Hair carries traces of substances from food, drink, drugs (i.e. amphetamine, ecstasy, opiates, benzodiazepines, cocaine, cannabis) or the air you breathe. Information from these samples can be analysed along with information from questionnaires that all the study participants have filled in. This will enable us to show whether any of these substances causes harm and if so what a safe level is.

What do I have to do if I agree to give a hair sample?

We would like to cut a sample from close to your scalp, keeping the hairs together in a bundle. You can decide where we do it, such as at the back just above the hairline where it will not show. The little bundle of hair needs to be about 2mm across ideally at least 3cm long. If it is much shorter it needs to be a bit thicker to provide enough hair for analysis.

Urine Sample

Why do you need urine samples?

The kidneys filter your blood, remove substances you don't need and excrete them in the urine. Therefore urine can tell us about things that you may have been exposed to. It can also give a measure of your body's responses to its environment. For instance, it can show how your body reacts to things like viruses, pollen or certain foods because of the substances released by the tissues which can be measured in the urine.

We would like to freeze and store some of your urine for future research.

You will also be offered the chance to take part in the National Chlamydia Screening Programme. *Please read the enclosed information sheet and leaflet before deciding whether to have this test or not.*

What do I have to do if I agree to give a urine sample?

You will need to give us a sample sometime during your visit. A member of staff will explain what to do (discreetly!) and you will find the instructions in the designated toilets.

Will you link information from the samples to me?

All samples and other information from you have a number put on them and your personal details removed as soon as we receive them. We can then link information about the same person together by these numbers but we do not link it to any individual – or to you - just to a number.

The G-Force Sensor

A study investigating the relationship between physical activity and bone development in young people

What is the purpose of the study?

Through this study, we want to gain an understanding of how physical activity relates to bone development in young people, like bone size and shape. We also hope to use the G-Force information in relation to body size, physical fitness and the activity information we have collected at previous visits.

What will happen?

The G-Force sensor is a little plastic device, which we would like you to wear on your waist for 7 days. This is starting first thing in the morning the day after you came to see us, until you go to bed at night. We would also like you to fill in a timesheet of when you wore the monitor over the 7-day period. At the end of the 7 days we will need you to post the G-Force Sensor and timesheet back to us.



Is there another way of doing this?

There is no other direct way of doing this. G-Force sensors are the only devices in the world that directly measure activities related to bone development over a 7-day period. The sensors have been developed especially for Children of the 90's.

Are there risks in wearing the G-Force Monitor?

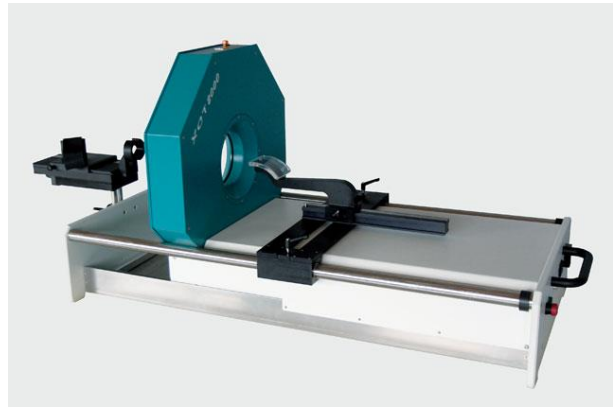
There are no risks or disadvantages associated with wearing the G-Force Sensor. You will still be able to do all of your normal daily activities.

What will happen if I change my mind?

You can withdraw from the study at any point during the 7 days, without having to give us a reason. You would just need to post the equipment back to us, so we can make sure that your information is deleted.

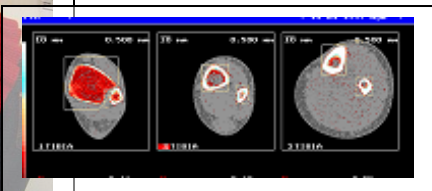
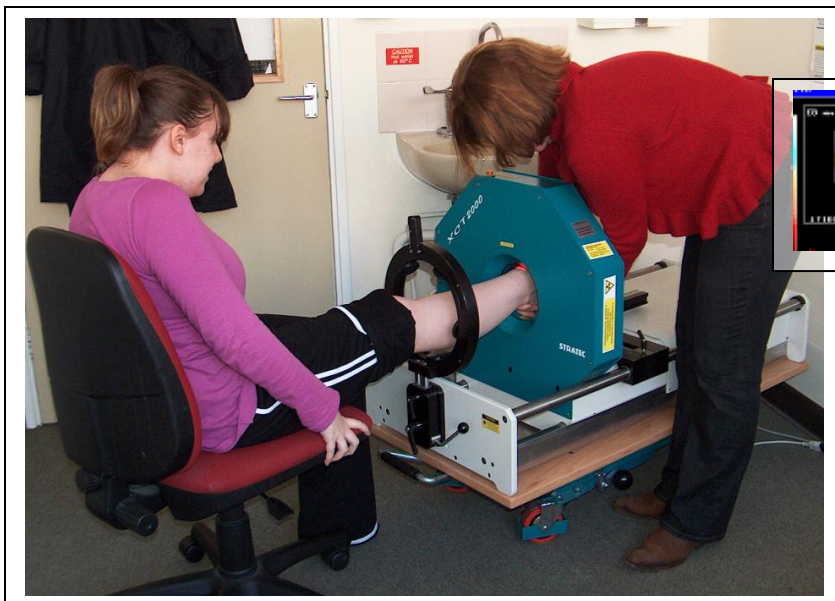
pQCT Scan through lower leg

If you have visited us before you have probably had several DXA scans so far and you may have also had a pQCT scan of your leg at your last visit. A **P**eripheral **Q**uantitative **C**omputerised **T**omography scan looks at the strength and quality of bones.



These scans give us important information about the density of your bones. Linking information from these scans with other data from all of you we can piece together all the factors, which contribute to bone density.

The CT scan tells us about the internal structure of bones and the way it varies between people and why. This internal structure may be important in predicting who is at risk of breaking bones and of osteoporosis in later life. Finding that out may lead to better screening and treatment of those at risk.



Our pQCT machine gives a cross-section of the lower leg showing the internal structure.

Your leg will be placed through the 'polo' shaped scanner. Taking the picture takes about 90secs.

Is it safe?

The pQCT uses tiny doses of X-rays like the DXA. The dose is less than 1 microsievert, which is well under the level of background radiation exposure that we all receive of 8 microsieverts per day.

Questions, questions

Interview session

This session is all about the way you feel, and how you react to people around you. We want to find out how you and the other young people in the study change over the next few years so we can build up a picture of teenagers and how they behave. We hope to understand why some young people find this stage of their lives easy and others struggle. (Remember – this is all totally confidential.)

- **Unusual experiences**

We will ask you some questions to find out more about unusual experiences or events that young people have experienced. Have you ever thought you have heard anything strange? Have you ever been aware of any unusual sensations? Have things ever looked or sounded odd or abnormal?

- **Handling difficult situations**

We will ask you to think about some difficult situations that might happen to you in everyday life and how you think and feel about them. For instance, getting a low mark in an exam or receiving a negative job evaluation.

- **Computer tasks**

You will be asked to complete some short computer tasks looking at decision making, memory and feelings. These tasks will take about 20 minutes.

If you are worried about any of the issues in these sessions, we can tell you how to contact people who can give you help and advice. If there is a really serious problem which puts you at risk and you have not been able to talk to any adults about it, we will discuss this with one of the doctors who work with us who may be able to help you.

Computer questions

There are questions about:

- school/college
- risk and gambling
- alcohol, cigarettes and other drugs
- sexual health
- your behaviour



Don't forget
You are free not to
answer any question if
you do not wish to

Paper questionnaires

These ask about:

- muscle and joint pain
- fractured bones
- your teeth
- life events
- menstruation (for females)

The Artery Study

In this study we will measure the size of the major blood vessels and the speed at which the blood travels around the circulation.

Why are you doing this research?

We are interested in finding out more about fat, cholesterol, calcium, and other substances found in the blood. Over time, these can harden and narrow the arteries reducing the flow of oxygen-rich blood to organs and other parts of the body. This can lead to serious problems in adulthood, including heart attacks or strokes.

The findings from this study will provide important information about how your lifestyle and health affect your arteries and how this might be used to develop prevention studies. Some of you may have taken part in a previous Children of the 90s arteries study if you came to Focus@10. Measurements this time will be compared with those earlier tests to see how your arteries have changed.

What would I have to do?

Neck scan:

We will assess your arteries to check that they look healthy and work well. Firstly, we will ask you to lie down on a couch for a few minutes to allow you to rest. We will put a small amount of gel onto your neck and record pictures of the main blood vessel (carotid artery) in your neck using an Ultrasound Machine. This is a completely painless technique and takes a few minutes, and you will need to stay really still. You will be able to see your artery on the screen. We also put a blood pressure cuff on each arm for a few minutes to measure your blood pressure.



Ultrasound image of Carotid Artery

Measure the speed at which your blood flows round your body

This test is called pulse wave velocity. It measures how elastic your arteries are. We will use cuffs (like blood pressure cuffs) around your wrist, leg and neck for a few minutes. We will then take measurement between your neck, arm and leg and calculate how long it takes for the pulse wave to travel between the two recording points.

Does it hurt?

The ultrasound scan of your neck is completely painless. The cuffs around your neck and wrist are not very tight so you will not feel any discomfort. The cuff around your leg does feel tight but will take only a few minutes.

Do I have to take part?

Taking part is entirely voluntary, like everything else in the Children of the 90s study. If you don't want to do this part of the visit, or if you change your mind during the session, just tell us. It won't affect your participation in the study in any way.

Who will see the results?

The results are stored with an individual ID number but no name or personal details are attached. They are used only by Children of the 90s researchers and collaborators.

Measurements

We'll take some basic measurements like weight, height and blood pressure.

Is it safe?

There are no risks to these tests, although the blood pressure cuff around your forearm does feel tight.

What exactly is blood pressure?

Blood pressure is the amount of pressure exerted on the walls of the arteries as the blood moves through them. It is measured in millimetres of mercury (mmHg). Both the systolic and diastolic pressures are measured, and these figures are usually shown with systolic pressure first, followed by diastolic pressure.

- Systolic pressure is the blood pressure that is exerted when the heart beats and forces blood around the body.
- Diastolic pressure is the measure of blood pressure when the heart is resting between beats.



So if your blood pressure is '120 over 80', or 120/80mmHg, what it means is that you have a systolic pressure of 120mmHg and a diastolic pressure of 80mmHg.

It is important to measure both as the systolic reading gives the maximum pressure and the diastolic the resting or base level.

Normal blood pressure in young adults can vary between 90/60mmHg and 135/85mmHg.

Children of the 90s want to study your blood pressure to see what factors affect it and to look at how this fits with the picture of your health overall.

General information

There is no need to take your clothes off to do these measures.

The measures are taken in a private room; no one apart from the measurer will see the results.

All the data will have had your name removed by the time it is analysed by researchers.

Will my taking part in Focus17 be kept confidential?

'Children of the 90s' takes data security very seriously. We work with the University of Bristol to develop safe systems and we have our own Children of the 90s computer team who work on this. All the people who use the information you give have a duty of confidentiality to you as a research participant and we will do our best to meet this duty.

HOW WILL MY DATA BE COLLECTED?

Everything you tell us is recorded under a series of numbers, not your name. All the data will either be typed into a computer program or written on a sheet that will be scanned into a computer.

WILL ANYONE BE ABLE TO CONNECT THE RESULTS OF TESTS TO ME?

No, all information in the 'Children of the 90s' study is kept separate from your name.

- Researchers who use the data don't see your name or address, just an anonymous ID number
- The staff who run the study see your name and address, but they don't have access to the data – no one else sees your name or address

WHERE DO YOU KEEP IT ALL?

All the information you give us is kept by 'Children of the 90s' and stored on secure computers run by the University of Bristol. Researchers are only given access to the parts of the data that they need. The samples you give are all stored in our laboratories, which you need an access code to get into. Small portions of samples labelled with an anonymous ID number are sent to specialised laboratories all over the world for analysis.

HOW LONG WILL YOU KEEP THE DATA FOR AND WHAT WILL HAPPEN IF YOU DISPOSE OF IT?

The longer 'Children of the 90s' continues, the more valuable it becomes. The aim is to use these data to study the Children of the 90s during the years they have children of their own – and beyond. The information you give could be used to answer many future research ideas. If we do have to dispose of any information or samples then we will do so securely.



WHAT RESEARCH ARE YOU GOING TO DO?

'Children of the 90s' currently has over 100 research projects and have published over 400 findings. We can't list them all here but you can read about them on our website:

<http://www.bristol.ac.uk/alspac/participants/findings/>

WHO DECIDES WHAT TO RESEARCH AND IF THE RESEARCH IS DONE PROPERLY?

Researchers from across the world use the Children of the 90s data to investigate a wide variety of issues. These research ideas and methods have been looked at and approved by:

- The Children of the 90s Executive committee, a group of the senior researchers and managers who work in Children of the 90s
- The Children of the 90s Law & Ethics Committee, an advisory group with researchers, lawyers and study parents who are there to protect your interests as study members
- TAP – our advisory group. This is a group of young study members who provide their personal perspective on what we do

All research connected to the NHS is looked at by an independent group of people, called a Research Ethics Committee to protect your safety, rights, wellbeing and dignity. The Focus17 study has been reviewed and approved by the North Somerset and South Bristol Research Ethics Committee.

**Do you have any suggestions?
Let our young person's advisory group
know. Email: tap@bristol.ac.uk**

GRACE (Growth related effects on heart function)

- The heart scan

What will happen to me if I take part?

We want to do an ultrasound scan called an “Echocardiogram” which looks at the function of your heart. The scan is not painful or harmful. In a curtained off area you will be asked to undress to the waist (including bra where applicable) and to change into a loose fitting top that we provide. The technician will ask you to lie on a couch on your left side. They will attach sticky leads to both of your shoulders and by the side of your body. These leads will show us your heart rhythm on a monitor. They will place some gel on your skin over the chest area; it is not harmful but may be a bit cold! They will then place a probe over the gel and look at pictures of your heart beating on the scanner monitor. The technician will look at two views of your heart, one from the middle of your chest, the other further down and round to your left side. Before positioning the probe the technician will fully explain the measurements they are about to take and ensure that you are comfortable with the procedure. The scan will take 30-40 minutes.



Is there anything to be worried about if I take part?

No. Ultrasound scans are completely safe and will not cause you any harm. All information collected about you during the course of this project will be kept confidential. The scans will not have your name on.

What are the possible benefits of taking part?

We do not think the scan will benefit you directly. It will help us learn more about the development of the heart from birth to adulthood. However if the technician noticed an anomaly the scan would be shown to the study physician who would send you a letter for your GP if necessary.

Who has approved and funded this study?

We have received funding from the British Heart Foundation to carry out this research and the Local Research Ethics Committee has approved it.

It's your choice – you can always change your mind! You don't need to tell us why and it won't stop you doing other things for Children of the 90's.

ELBA

- 24 hour blood pressure and activity monitoring



Ambulatory BP monitor

Your blood pressure is measured half hourly during the day and hourly during the night. Each measure takes about 1 minute but occasionally another measure is taken 2 minutes later. You will hear a 'beep' when the monitor is just about to take a reading. When you feel the cuff tighten around your upper arm, if possible, stop all movement and do not talk. The machine shows readings for the first two hours and then only a blank line.

When you go to the bed the machine can go under the pillow keeping it connected to the cuff on your arm. You may experience pins and needles during the measurement but this is only temporary. Do not remove the cuff or press the on/off switch. Turn off only in an emergency or when the 24-hour monitoring period is complete.

BP wrist monitor

The BP watch takes a recording every 15mins and will 'beep' just before it does this. When you hear the 'beep' you should again try and keep still for 20-30 seconds but you will not feel anything. The watch must stay on your wrist for the whole 24 hours. If it is taken off then all recordings will stop. You will be shown how to turn the 'beep' off before you go to bed.

Actigraph activity monitor

The activity monitor should be fitted around your waist for the whole 24 hours. It will not beep and you will not feel it taking any readings. We want you to keep it around your waist even when you are in bed so we can see how much you move in your sleep!

General advice

Please do not play with any buttons on the monitors. It may change the settings and we could end up with no information from them. Do not bath, shower, go swimming or do any activity that may get the monitors wet. Do not play any contact sports or any vigorous activities, which could damage the monitors or cause you any injury if you fall over onto them.

Please keep a record of your activities during the 24-hour period on the activity record (especially writing in when you go to bed and when you get up). Try to keep to a normal daily routine as possible.

Blood Vessel Study

- An ultrasound scan of your arm

WHY ARE YOU DOING THIS RESEARCH?

We are interested in finding out more about the early stages of arterial disease. To do this we need to study how the blood vessels work in young people.

HOW DO YOU LOOK AT THE BLOOD VESSELS?

We use a simple non-invasive ultrasound technique to study the main blood vessel in the arm (brachial artery) to try and understand how arteries work. We will use an ultrasound machine, similar to that used in pregnancy, to image the brachial artery in the upper arm. This allows us to investigate the inner lining of the blood vessels. By using this and other measures of arterial stiffness we hope to further our understanding of blood vessel function.

WHAT WILL HAPPEN IF I TAKE PART?

For this scan the procedure is exactly the same as was performed when you were 10 years old. We will ask you to lie down on the couch. We will put three heart rate electrodes on your chest to measure your heart rate and we will also measure your blood pressure. We will then look at the main blood vessel in the right arm and measure its width and the movement of the vessel walls with each pulse, using an ultrasound scanner. This sometimes takes a few minutes so we ask you to stay really still. A cuff will be inflated around the lower arm for 5 minutes and then released. The increase in blood flow caused by releasing the cuff and the change in blood vessel size will be measured. When the cuff goes down you need to stay really still so that we can see if there are any changes. If you listen carefully you can hear your blood flowing through your arm. We will give you a photograph of your artery to take away.

DOES IT HURT?

The ultrasound is completely painless. The blood pressure cuff around your forearm does feel tight and your fingers will probably go tingly or numb but everything goes back to normal very quickly when the cuff goes down.

WHO CAN I ASK ABOUT THIS STUDY?

Please ask the people doing your scan if you want to know more about what will happen and the possible results.

WHO WILL SEE THE RESULTS?

The results are stored with an individual ID number but no name or personal details are attached. They are used only by Children of the 90s researchers and collaborators.

Any Questions?

WILL YOU LET ME KNOW THE RESULTS FROM THE MEASURES?

Normally we do not give back results. For most of the measures there are not clear 'good' or 'bad' results, and we would not want you to change the way you live your lives based on this feedback. 'Children of the 90s' is an observational study where we want to record details of your lives but try not to influence your health and development in any way.

However at Focus17 we do tell you if:

- The iron levels (haemoglobin) in your blood are low, this can indicate anaemia
- The glucose (sugar) levels in your blood are outside the normal range
- The cholesterol levels in your blood are outside the normal range
- Your blood pressure is high
- The 'National Chlamydia Screening Programme' will feedback results using the contact method you choose and only if you agree. Please see the separate information leaflet

WHAT HAPPENS IF I CHANGE MY MIND ABOUT DOING A MEASURE OR DECIDE I WANT TO STOP THE VISIT?

It's your choice, and you can change your mind at any point, it won't stop you from being in Children of the 90s. There's no pressure, we won't ask why and you will still get your thank you voucher.

If you have changed your mind then you can ask us to destroy your data and/or samples

- It is not possible for us to destroy information that has already been made available for research
- Samples - We would prefer to be able to carry on using the samples you have given us, but if you would like them to be destroyed then we will do so unless they cannot be identified due to way they have been processed
- DNA – We would prefer to be able to carry on using your DNA data in our research but if you wish for us to stop then we will remove the main stocks and destroy them. Your samples will not be used for further tests, and we will not use the results of any analysis being carried out at the time of your withdrawal of consent

We will do all we can to meet your wishes wherever possible.

WHAT HAPPENS IF I CAN'T REMEMBER WHAT SESSIONS I DID OR CONSENTED TO?

If you can't remember then get in touch and we will send you copies of your consent forms and a list of the sessions you took part in.

PLEASE GET IN TOUCH IF YOU HAVE ANY OTHER QUESTIONS

WHO IS FUNDING THE RESEARCH?

Our funding comes from different sources, mainly charities, publicly funded research organisations and we have support from the University of Bristol.

The Focus17 funders are:



FEEDBACK OR CONCERNS?

If you have any questions then call our clinic on 0117 3310011 (or text on 07789753722 and we'll call you back)

If you have any suggestions please let us know. You can email:

- the clinic office: focus-admin@bristol.ac.uk or
- or our Young Person's Advisory Group: tap@bristol.ac.uk

If you have a concern about the study then you can contact our family liaison team:

- alspac-project@bristol.ac.uk
- Tel: 0117 3310010

If you remain unhappy and wish to complain formally, you can do this by contacting our Executive team:

- alspac-exec@bristol.ac.uk

**Want to know about some of our findings?
Check out our website:
<http://www.bristol.ac.uk/alspac/participants/findings/>**



***We look forward to seeing
you at Focus17!***



Focus17

Oakfield House, Oakfield Grove
Clifton, Bristol BS8 2BN

Tel: 0117 331 0011

There is an answer phone on this line

E-mail: focus-admin@bristol.ac.uk

Consents

I have read and understood the information sheets on the following tests and understand what they will involve. I understand that all tests are completely voluntary. The purposes and possible risks have been explained to me and I have been given an opportunity to ask questions. I know that the tests will end if I ask for them to stop.

Study Participant:

I consent to those tests which I have marked with a cross in column 1 and initialled in column 2 overleaf. I am happy that the data are stored with individual ID but no name or personal details attached, for storage and use by Children of the 90s' researchers and collaborators.

I understand that I need to indicate, by putting a cross in the box next to the test in column 3 and my initials in the box beside it in column 4, whether or not I wish to be informed if the results of tests marked * give any cause for concern and I wish to receive a letter to give to my GP. I understand that if I do not cross the box and initial, I will not be told.

Leave boxes blank if you DO NOT consent to the tests.

You must also obtain the consent of your parent/guardian on this form or we will not be able to perform any tests.

Parent/Guardian:

I consent to those tests which I have marked with a cross in column 5 and initialled in column 6 overleaf. I am happy that the data are stored with individual ID but no name or personal details attached, for storage and use by Children of the 90s' researchers and collaborators.

Leave boxes blank if you DO NOT consent to the tests.



	Consent to test		Consent to inform		Parent/guardian consent	
	1 Cross box	2 Initial	3 Cross box	4 Initial	5 Cross box	6 Initial
(a) Whole body DXA scan	<input type="checkbox"/>	<input type="text"/>			<input type="checkbox"/>	<input type="text"/>
(b) Hip DXA Scan	<input type="checkbox"/>	<input type="text"/>			<input type="checkbox"/>	<input type="text"/>
(c) PQCT scan of lower leg	<input type="checkbox"/>	<input type="text"/>			<input type="checkbox"/>	<input type="text"/>
(d) Blood pressure*	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>
(e) Face shape image	<input type="checkbox"/>	<input type="text"/>			<input type="checkbox"/>	<input type="text"/>
(f) Artery scan	<input type="checkbox"/>	<input type="text"/>			<input type="checkbox"/>	<input type="text"/>
I understand that donated blood will be considered a gift but I will have the right to withdraw permission for analysis.						
Blood sample for:						
(g) Haemoglobin (test for anaemia)*	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>
(h) Glucose (sugar)*	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>
(i) Lipids (forms of cholesterol)*	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>	<input type="checkbox"/>	<input type="text"/>
(ii) Cotinine	<input type="checkbox"/>	<input type="text"/>			<input type="checkbox"/>	<input type="text"/>
(j) Storage for future research	<input type="checkbox"/>	<input type="text"/>			<input type="checkbox"/>	<input type="text"/>
(k) Hair sample	<input type="checkbox"/>	<input type="text"/>			<input type="checkbox"/>	<input type="text"/>
(l) Questions about moods and feelings <small>please note, some questions will be recorded solely for quality purposes</small>	<input type="checkbox"/>	<input type="text"/>			<input type="checkbox"/>	<input type="text"/>
(m) G-Force Accelerometer	<input type="checkbox"/>	<input type="text"/>			<input type="checkbox"/>	<input type="text"/>
(n) Abdominal (liver & spleen) ultrasound	<input type="checkbox"/>	<input type="text"/>			<input type="checkbox"/>	<input type="text"/>

Study Participant AND Parent/Guardian: Please sign and date the form below.

STUDY PARTICIPANT CONSENT

I am the person attending Focus 17 and I consent to the tests that I have crossed and initialled above.

Signature Date / / 2 0

Initial Last Name

PARENTAL CONSENT

I am the study participant's parent (or guardian) or have parent's permission to give consent for the tests that I have crossed and initialled above.

Signature Date / / 2 0

Initial Last Name

Office use: Parental consent by phone. Witnessed consent attached.

Draft

The University of Bristol holds legal liability insurance in the event that any participant is injured due to any negligence on the part of the University.





Focus17

Oakfield House, Oakfield Grove
Clifton, Bristol BS8 2BN

Tel: **0117 331 0011**
There is an answer phone on this line
Email: **focus-admin@bristol.ac.uk**

Visit ID no

URINE CONSENT

I have read and understood the information sheets about urine collection and understand what the sample will be used for. I understand that all tests are completely voluntary. The purposes and possible risks have been explained to me and I have been given an opportunity to ask questions.

Study Participant:

I consent to giving a urine sample for Children of the 90's and my sample being used for the tests below as I have indicated. I have marked those I consent to with a cross in column 1 and initialled in column 2 overleaf. I am happy that the data are stored with an individual ID but no name or personal details attached*, for storage and use by Children of the 90's researchers and collaborators.

Leave boxes blank if you DO NOT consent to the tests.

You must also obtain the consent of your parent/guardian on this form or we will not be able to perform any tests.

Parent/Guardian:

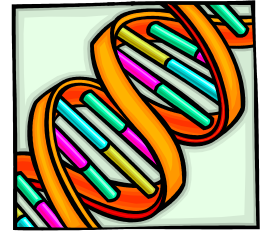
I consent to those tests which I have marked with a cross in column 3 and initialled in column 4 overleaf. I am happy that the data are stored with an individual ID but no name or personal details attached*, for storage and use by Children of the 90's researchers and collaborators.

Leave boxes blank if you DO NOT consent to the tests.

** see separate information sheets and consent form for National Chlamydia Screening Programme*

DNA, GENES, and CELL-LINES.....

Our genes are important in making us more or less likely to develop many common diseases. We all have a slightly different set of genes in our bodies. To help us look at these differences and understand the causes of diseases, we have been asking the young people coming to Focus visits to provide a small blood sample which can be treated so that it provides a never-ending supply of DNA. These cells can also be studied to provide a more detailed description of how some parts of the body work.



Question: What are genes?

Answer: Genes are the instructions which determine growth and development of all living organisms.

Question: What is DNA?

Answer: DNA is the chemical language in which are genes are written.

Question: Why do you want to study my DNA?

Answer: Although we all have essentially the same genes as each other, there are many small differences which some of us have and others do not. These different versions of our genes make us more likely or less likely to develop many common diseases, such as allergies (like asthma), or diabetes or heart disease. We want to discover which versions of particular genes increase the risk of these diseases and which versions protect us.

Question: Is it just genes that cause disease?

Answer: No. We already know that many of our common health problems are partly caused by genes and partly by our environments.

Question: How will my DNA help?

Answer: By discovering the way in which genes and the environment cause common diseases we will be able to discover what makes people more likely to develop diseases like asthma or diabetes. We can then develop better ways of preventing or treating them.

Question: Why do you need more DNA?

Answer: We each have about 100,000 genes. With your permission, we want to study many of these genes, but the DNA we have collected so far will run out before we can complete this work. We would like to collect a blood sample from you and treat the cells from the blood so that they can be stored indefinitely as 'immortalised' cell-lines. These cells can be used to make more DNA whenever it is needed.

Question: What are *immortalised* cell lines?

Answer: Cells are the building blocks of the body. Skin, muscle, bones, blood, and all the other parts of our body, are made up of millions of tiny cells. Each cell has a copy of all our genes. If we take cells from our bodies, we can only keep them alive for a limited time. However if cells are



treated with a virus they can be kept alive indefinitely - they become *immortalised*.

Question: Do *immortalised* cell-lines have other uses?

Answer: Yes, our study is unique in its detailed descriptions of its participants gathered over many years (as you have probably realised!). One of the ways in which we may be able to add further important information is by studying *immortalised* cell lines. Cells from cell-lines retain some of the basic features, as well as the DNA, of the people from whom they were derived. For example, one study found that cell-lines from people with raised blood pressure grow faster than those from people with normal blood pressure. Studying cells in this way may provide important stepping-stones that will help bridge the gap between genes and the whole person and improve our understanding of how the two are linked.



Question: Will anyone be able to connect the results of tests to me?

Answer: No, all the information in the 'Children of the 90s' study is kept separate from your name. No one who works with samples or answers to questionnaires is allowed to know who they came from. This means that the study is completely confidential.

Question: Where are my DNA and/or cell-lines kept?

Answer: The main stocks of DNA and cell lines are stored here in Bristol. They will be kept indefinitely. The DNA (with an anonymous number) is also sent to specialist research laboratories in the UK and abroad for analysis, and the results are returned to us. Outside researchers who work with Children of the 90's data or samples are bound by a strict code of conduct and have no access to information that would identify study participants.

Question: Would you ever sell my DNA or cell-lines?

Answer: No, we would never sell these, or any of the information you have given us.

Question: If the Children of the 90s study makes cell-lines from my blood, can I be sure they will not be used for cloning?

Answer: Yes, you can be sure. The use of human tissues, including cell-lines, is strictly controlled. Charities and government organisations which give money for research, Bristol University and the Children of the 90s study ethics committee, which includes parents of study children, would not allow human cloning.

Question: If I change my mind later and don't want you to keep my DNA or cells, what should I do?

Answer: You can change your mind at any time. Write to us and say you don't want us to keep your DNA or cells. We will remove them and destroy them.

We welcome any further questions which you would like answered. Please phone 0117 331 0010, or talk to the Focus staff and ask to be put in contact with Dr Sue Ring.





Focus17

Oakfield House, Oakfield Grove
Clifton, Bristol BS8 2BN

Tel: 0117 331 0011

There is an answer phone on this line

E-mail: focus-admin@bristol.ac.uk

Visit Number _____

Permission to use blood sample for cell lines

After processing the name will be taken off the blood samples. The cell lines and DNA samples will be stored with no names attached to them. Results will be used for statistical purposes only and not linked to named people.

CONSENT

The purposes and possible risks in having blood taken have been explained to me. I understand that donated blood will be considered a gift but I will have the right to withdraw permission for analysis. (If you consent, please cross **one** of the boxes below)

A sample for cell lines ('immortalised' DNA) 1

OR

A sample for DNA only 2

I understand that the main stocks of DNA and/or cell lines will be stored in Bristol, but that the DNA/cell lines (with an anonymous number only), or information about the sequence of my DNA, may be sent to specialist research laboratories in the UK and abroad for analyses and the results returned to Children of the 90s. Researchers at these laboratories have no access to personal information about study participants. I agree that the information about my genes can be analysed together with information about my health, disease and life style factors in order to undertake research into biological or genetic factors affecting the risk of developing a range of common medical conditions. I understand that any such analyses will only be undertaken on data from which all personal information has been removed and replaced with an anonymous code.

I am the young person participating in the study.

Signature

Date

 / / 20

Initial

Last Name

PARENTAL CONSENT

I am his/her parent (or guardian) or have parent's permission to give consent.

Signature

Date

 / / 20

Initial

Last Name

Draft

The University of Bristol holds legal liability insurance in the event that any participant is injured due to any negligence on the part of the University.





ALSPAC
Oakfield House
Oakfield Grove
Clifton
Bristol BS8 2BN
Tel: 0117 xxx xxxx
Email: xxx@bristol.ac.uk



Breast Tissue Composition in Young Women

1. THE STUDY

What is the study about?

We wish to study whether breast development in young women is influenced by genes and hormones. We cannot be sure but hope that such knowledge will help us to improve our understanding of what causes breast cancer much later in life.

Why have I been contacted?

We are studying only some of the ALSPAC Children of the 90's. This is because we are using MRI scans and each scan costs a lot. We are inviting young women who have attended previous clinics quite regularly. **However, women who are pregnant, or think they may be pregnant, should not take part because the findings of the study will be distorted by pregnancy.**

How am I involved?

If you decide you are willing to take part, we would like you to fill in the participation slip and return it to us in the stamped envelope provided. We will then contact you to arrange for you to attend the University of Bristol Clinical Research and Imaging Centre (CRIC) to have your MRI scan at a date and time of your convenience. You will be asked to sign a consent form and fill in a short questionnaire.

We are also asking whether you would be willing to give us a small blood sample (5 ml) to measure hormone levels while you are attending the Bristol CRIC for your MRI appointment.

Lastly, we are hoping you would also provide us with 7 repeat urine samples, taken on specific days throughout your menstrual cycle. If you are willing to do this, we will provide you with containers and stamped envelopes to facilitate this process.

What will be done with the information I provide?

The information that you provide will be used for medical research only. We will use the data from the questionnaires, the MRI, and the blood and urine samples to learn how genes and hormones influence the development of the breast in young women. This should help us to understand what causes breast cancer much later in life. All information that is collected about you during the course of the research will be kept strictly confidential. Only the health professionals directly involved in the study will have access to these data. We will make sure that your name and address are kept

separately from any other information about you, so that this information could not be linked back to you by anyone outside the study. We will not, under any circumstances, release your contact details to any outside party. Only anonymised information may be released to other researchers.

Will I see the results of the study?

All results obtained during this study will be used for medical research purposes only. Individual results will not be reported back to women participating in the study because we do not yet know enough about such factors for the information to be of current use to your doctor. We will, however, be happy to tell you about the results of the study and, by finding out more about the factors that are involved in breast development we hope we can help with the care of women in the future. A summary of the results will be posted at the ALSPAC website.

Do I have to take part in the study?

It is up to you to decide whether or not to take part in this study. If you do decide to participate you are free to withdraw at any time and without giving a reason. A decision to withdraw at any time, or a decision not to take part, will not affect the standard of medical care that you receive.

How can I obtain more information?

Please ask us if there is anything that is not clear or if you would like more information regarding the study. You can contact us by post, telephone and email (details as above). If we cannot take your call immediately, please leave a message and we will phone you back. We will be happy to answer your questions.

2. THE MRI

What is an MRI scan?

Magnetic Resonance Imaging (MRI) is a medical technique that provides a picture of the structures located inside the body. In MRI scans, there is no exposure to x-rays or other forms of radiation.



u-

How does an MRI scanner work?

You lie inside a large, cylinder-shaped magnet, which sends radio waves through the body to make it emit signals. These signals are measured by a computer and used to create a picture of the internal structure of the body.

Can anyone have an MRI scan?

If you have a cardiac pacemaker, have had heart surgery, surgery to head, neck, eyes or ears or a brain haemorrhage then it is best to avoid an MRI scan. If you think you may be pregnant you will not be eligible to take part in the study. Any body piercing would also need to be removed for the MRI scan.

Are there any risks from MRI scan?

No. MRI does not involve exposure to x-ray radiation. This technology has been used for medical imaging since the 1980s and is considered very safe. Please discuss this further with your GP if you have any concerns.

Where will this take place?

It will take place at the University of Bristol Clinical Research and Imaging Centre (CRIC-Bristol), which is on St Michael's Hill in the city centre. We will cover all of your travel expenses to and from the CRIC-Bristol.

When will this take place?

It will take place at a date and time of your convenience.

Do I have to prepare?

You can eat or drink normally on the day of your scan.

What do I wear?

Please ensure the clothing (including your bra) that you wear to the scan contains **no metal**. For example, a sweatshirt and drawstring jogging trousers would be ideal.

How long will it take?

Your visit to CRIC-Bristol will take less than 1 hour. The scan in itself will take less than 15 minutes.

What will happen?

For the MRI scan you will be positioned comfortably on a scanning bed that slides into the tunnel-shaped magnet. When the scanner is turned on, it makes loud humming and knocking sounds. Earmuffs or earplugs will be provided. An intercom system allows the young person and technologist to speak to each other. The scan will take less than 15 minutes and you will be asked to keep very still during this time. This procedure is not painful, just noisy. **If you have a fear of enclosed spaces (claustrophobia) it is best not to participate in this study.**

Are there any benefits?

Almost certainly not. There are no direct benefits to you from having these tests, but they are very helpful for research purposes. In very rare cases it is possible that the scans will pick up a problem with your breast tissue. At your age we think the likelihood of this is so small that it probably will not occur in any of you. But if the radiologist did see something that they were concerned about, they

would look carefully at your scan films and discuss these with other doctors. Doctors would send you a letter to take to your GP if there were signs of a serious problem only if you indicated in your signed consent form that you would like to be informed of this.

How will I get to the Clinical Research and Imaging Centre (CRIC-Bristol)?

We cannot arrange transport to the CRIC-Bristol for these tests and so we would like you to arrange your own transport and claim the cost back. We would suggest you take a taxi to and from home and we will pay you back for the cost of this. **Please keep the receipts from the taxi** and send them back to the study team with the form, in the envelope that you will be given when the scan has been completed at the CRIC-Bristol. We will send you a cheque for the full cost of your travel to and from the CRIC-Bristol.

3. THE BLOOD SAMPLE

If you are willing to participate in the study and provide a blood sample, a nurse at the CRIC-Bristol will take a small blood sample after you have completed your MRI examination.

4. THE URINE SAMPLES

If you agree to participate in the study, we will give you a pack with all the equipment you need for the urine collection. You will be asked to collect urine samples at particular days within your menstrual cycle, and post them back to our laboratories in stamped envelopes that we will provide. If, for any reason, you are unable to collect urine during your next cycle (for example, if you are going on holiday) this is not a problem. You can wait until your next cycle when it is convenient for you.

Thank you for reading this participant information sheet and
considering participating in this study

Ref:



Breast Tissue Composition in Young Women

CONSENT FORM

Please initial box

1. I confirm that I have read and understood the INFORMATION SHEET dated , for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I agree to having an MRI scan of my breasts.
4. I am willing to provide a blood sample (10 ml) for measurement of hormones I understand that donated blood and urine will be considered a gift but I will have the right to withdraw permission for analysis.
5. I agree for my samples to be stored by ALSPAC for future research
6. I am willing to provide repeat urine samples.
7. I agree to take part in the above study.
8. I would like to be informed in the unlikely event that something suspicious is found in my MRI scan or hormone tests.

Full Name

Signature

Date



FOCUS @24+



INFORMATION FOR YOU



Avon Longitudinal Study
of Parents and Children

This booklet has information about your Focus@24+ visit.
If anything isn't clear or you have a question,
please get in touch.

Do you need this booklet in another format like
large print, audio or a different language?

If you do, please let us know.

☎ 0117 331 0010

✉ info@childrenofthe90s.ac.uk

🌐 www.childrenofthe90s.ac.uk



HOW TIME FLIES!



CAN YOU BELIEVE IT'S BEEN SEVEN YEARS SINCE FOCUS@17?

Since then:

- ▶ Thousands of participants have helped us with our research 
- ▶ 3,000 mothers and 2,000 fathers have attended their own clinic
- ▶ 300 babies and young children have taken part in COCO90s 
- ▶ Nearly 1,000 brothers and sisters have joined Children of the 90s
- ▶ We've published our 1,000th academic research paper 
- ▶ We've been awarded the Bristol Genius Award

We couldn't have done any of this without you and that's why we'd like you to take part in Focus@24+. The more information we have about you, the better picture we can build up of the health of your generation.

No one else can give us the same information you do. No one else has your genes or has lived your life. That makes you unique and really important to us.

So, please read on to find out what's involved in Focus@24+, then please get in touch to arrange an appointment. You can do this:

- 📺 online at www.childrenofthe90s.ac.uk/bookings
- ☎ by phone on 0117 331 0010
- 📄 by completing and returning the reply slip at the bottom of the attached letter

If you have any questions or just want to find out more, please get in touch.



WHAT YOU NEED TO KNOW BEFORE YOUR FOCUS VISIT

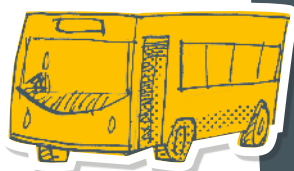
WHERE TO GO

Children of the 90s Focus Centre
Oakfield House, Oakfield Grove,
Bristol, BS8 2BN



We are close to Whiteladies Road, near bus routes:
1, 2, 3, 4, 8, 9 and 72.

Please check the First Bus website before travelling
for the latest travel updates and route changes.
<http://www.firstgroup.com/>



TRAVEL AND EXPENSES

We'll help you with your travel expenses, book local taxis and arrange overnight accommodation for you if you need us to. Please get in touch if you need us to help you with your travel arrangements. There is free onsite parking. As a thank you for taking part, we'll give you a shopping voucher worth £40.



SPECIAL REQUIREMENTS

Please let us know if you have any access, dietary or other requirements.

TIME

Your whole visit will last between six and seven hours if you choose to do all the sessions.



CAFFEINE AND TOBACCO

Please try not to smoke or drink caffeine during your visit as this can affect some test results.

FASTING BEFORE YOUR VISIT

We would like you to fast for six hours before your visit, as we would like, with your written consent, to do some blood tests and a liver and a heart scan when you arrive. These are more accurate if you have not eaten for several hours beforehand. Please note: after you've had a light meal, we may need to ask you to fast for another two hours before your heart scan.

- You can have water at any time
- If you are using warfarin or heparin we will not take a blood sample
- If you are diabetic and using insulin (or have any other medical condition which means you should not go without food) please do not fast, although we will still ask for a blood sample

What happens if I forget to fast?

Fasting allows us to accurately measure sugar, fats and other substances in your blood and makes the liver scan more accurate. But if you forget just make a note of what you had to eat or drink and attend your visit as normal. We will still ask you if we can take a blood sample and do a liver scan.

When should I eat and drink?

If you're visiting in the **morning (before midday)**: Please **don't** have anything to eat (including sweets or chewing gum) or drink, apart from water, after waking up on the morning of your Focus visit and until you've given a blood sample and had a liver scan. **Do** eat the evening before – you can have a snack before bed.



If you're visiting in the **afternoon (at or after midday)**: Please **do** have a light breakfast before 06.00. Please **don't** have anything to eat (including sweets or chewing gum) or drink, apart from water, from 06.00 until you've given a blood sample and had a liver scan.





WHEN CAN I EAT?

Once you've completed any sessions that require you to fast beforehand, you can have a light meal in our free café, which has a selection of cereals, toast, pastries, sandwiches, fruit, yoghurt, snacks and hot and cold drinks. Let us know if you have any dietary requirements and we will do our best to accommodate them. You are welcome to bring your own food with you if you prefer.

WHAT TO BRING OR WEAR

- The medications and allergies questionnaire we sent you with your appointment reminder letter. Please complete this before your visit
- Loose, comfortable clothes (e.g. jogging bottoms or baggy leggings) and a top with sleeves that can be rolled up easily
- Flat, comfortable shoes
- Flesh-coloured or light grey underwear if you would prefer to wear underwear for the 3D body scan. Underwired bras cannot be worn in the 3D body scanner, so please make sure your bra is suitable
- Glasses if you normally wear them
- Please do not wear clothes with metal fastenings or metal zips and please remove any watches, earrings, body piercings or other metal objects before having the DEXA and 3D whole-body scans as metals can affect the results.

PREGNANCY

If you are pregnant or think you may be, we will not ask you to have a liver, heart or whole-body DEXA scan. We will not ask you to take salbutamol (Ventolin) during the lung function test.

TIMETABLE FOR YOUR FOCUS VISIT



- Arrive at the Children of the 90s Focus Centre for your visit. It will last just over six hours



- Meet a member of the team who will explain what's involved. There will be lots of time to ask questions



- If you're happy to continue, we'll ask you to sign a consent form. If you've given us your consent, we'd like to do some blood tests and a liver scan

- Time for a break and something to eat and drink in our cafe



- Then it's time for the rest of the sessions. Each one lasts between 5 and 35 minutes

- A member of staff will explain each session to you in turn. You can ask as many questions as you like along the way. You choose which sessions you want to do and you can stop or change your mind at any point during your visit

- At the end of your visit, we'll give you a £40 voucher to thank you for helping us with our research



- When you've finished, we can arrange a free taxi to take you home if you live locally.

The contents list is on the next page and the pages after that contain information about what's involved in each session. If you have any questions after reading the booklet, please get in touch.

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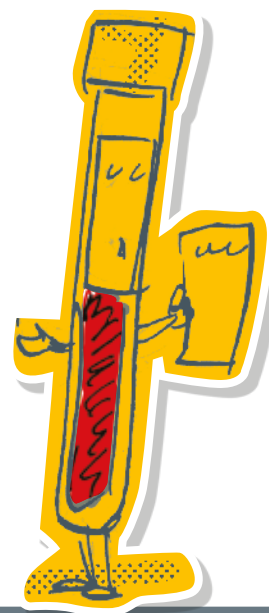
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SO WHAT'S INVOLVED?

INFORMED CONSENT



First a fieldworker will explain all the sessions to you and answer any questions you may have. Then they will ask you to complete and sign a consent form. You can withdraw from any or all of the individual sessions at any time. You choose how much or how little you'd like to do.



FASTING BLOOD SAMPLE



WHY DO I HAVE TO FAST BEFORE GIVING BLOOD?

We would like you to come for your Focus visit not having eaten or drunk anything, except water ('fasting'), for at least six hours. Some tests such as haemoglobin (a measure of anaemia), cholesterol, glucose (sugar) and liver function are best done after you have fasted.

WHAT IF I'M NOT ABLE TO FAST?

Don't worry. We'd still like to take your blood as it is very valuable for our research. Blood contains many different substances that change over time. That's why we ask you to give a blood sample at each Focus visit.

IS THERE ANY REASON WHY I SHOULDN'T FAST?

Please do not fast if:

- you have insulin-dependent diabetes
- you have recently begun treatment for anaemia
- you are currently taking anti-coagulants, such as warfarin or heparin
- you are feeling unwell on the day of your visit

WHAT IF I DON'T WANT TO GIVE BLOOD?

If you do not wish to give a blood sample or if we are unable to take a sample we will give you the option of providing a saliva sample instead.

WHAT'S INVOLVED?

One of our trained fieldworkers will take your blood sample while you are seated on a special couch. We will collect up to 50ml. That's about a quarter of a tea cup. If it's uncomfortable or you feel faint, you can ask the fieldworker to stop at any time.

We will ask your permission to collect a specific blood sample for **immortalised cell lines**. We will separate cells from this sample and treat them in a way which enables them to be grown continuously or frozen in a way which keeps them alive forever, making them immortal and allowing us to use them indefinitely. These are very useful for our research. They provide a never-ending supply of genetic material (such as DNA). They also retain some of your biological characteristics. We can grow the cells under different conditions and look for changes over time in the way the cells behave and for certain markers. We also look at how they differ from one person to the next.

For example, research has found that cell lines from people with raised blood pressure grow faster than those from people with normal blood pressure. Studying cells in this way helps bridge the gap between genes and the whole person and improves our understanding of how the two are linked.



WHAT WILL YOU DO WITH MY BLOOD SAMPLE?

We will count the number of red cells, white cells and platelets in your blood. We will test it for haemoglobin (a measure of anaemia), cholesterol, glucose (sugar) and liver function; in samples from women we will also test reproductive hormones. We will also store some for ethically approved research.

WILL YOU USE IT FOR DNA AND GENETICS?

Yes, with your consent we will extract DNA from your blood (or saliva) for genetic research. We would also like to extract RNA from your blood. This is the genetic material that carries out the instructions of DNA.

Although we all have essentially the same genes, there are many small differences between us. Different versions of our genes can make us more likely or less likely to develop common diseases, such as allergies (like asthma), or diabetes or heart disease. They can also affect our character and behaviour. We want to discover which versions of certain genes increase the risk of these diseases and which versions protect us from disease.

Even though genes do not change over life there is evidence that how they work does. That's why we would like a sample from you now even though you may have provided a DNA sample at an earlier Focus visit. Like other tests we do, our research on genes has no clear medical meaning at the moment. Therefore we will not tell you about these results.

HOW ARE THE BLOOD SAMPLES STORED?

The samples are stored with unique ID numbers so that we can link your test results to other data about you.

URINE SAMPLE

WHY DO YOU WANT A URINE SAMPLE?

Urine can tell us about the things our bodies have been exposed to and can measure our responses to the environment. For instance, it can show how our body reacts to viruses, pollen or certain foods.

WHAT'S INVOLVED?

We would like you to give us a small urine sample (about 1/3 of a cup).

WHAT WILL YOU DO WITH IT?

We will store it in a freezer for future research that looks at the chemicals your body has been exposed to. We will also look at how the body breaks down and removes certain molecules from the body in the urine.

IS IT SAFE?

Yes. There are no risks or benefits associated with giving a urine sample.



WHAT'S INVOLVED?

The tests will be carried out on some of the urine that you give to Children of the 90s. The only extra thing you will need to do is complete a consent form and an NCSP chlamydia test request form. The NCSP form will ask for your contact details and will go to the NCSP with your sample so that they can contact you with your results. This form will also ask about your recent sexual history and ethnicity but you don't have to complete these sections if you don't want to.

You will be contacted directly by the NCSP with the outcome of your test within four weeks, regardless of whether your test is negative or positive. If your test result is negative the NCSP will text or email you to let you know. If your test is positive, they will call you.

IS IT SAFE?

There are no physical risks involved but the benefit to you is that this test will identify whether or not you have chlamydia and/or gonorrhoea. If you do, you will be offered treatment which will prevent any long-term problems associated with these infections. If you have an infection and it is not treated, it may cause health problems. Most people who have these infections have no symptoms.

HOW RELIABLE ARE THE TEST RESULTS?

It is rare for the test results to be wrong but we will discuss this with you during your Focus visit. The NCSP will also discuss this with you when they talk to you about your test result. If you believe, for any reason, that the test result is incorrect, then you should contact your GP or local Chlamydia Screening Programme in the normal way to arrange to be re-tested.

WHO WILL KNOW ABOUT MY RESULTS?

- The NCSP will contact you directly about your results by phone, email or text and, with your agreement, will provide confidential treatment if you test positive.
- With your consent, Children of the 90s will be provided with your test results to conduct research into these infections. Your test results will be linked to your Children of the 90s ID but not stored with your name or address or other contact details.
- As a standard part of the NSCP activities, details of your result, but not your name or contact details, will be sent to Public Health England. This is so that they can count how many people in England have chlamydia and/or gonorrhoea.

NATIONAL CHLAMYDIA SCREENING PROGRAMME



If you give us a urine sample, we will ask if you would like to have it tested for chlamydia and gonorrhoea by the National Chlamydia Screening Programme (NCSP). We are offering you these tests regardless of whether or not you think you have been at risk of infection or have recently been tested. You do not have to undergo these tests if you don't want to and your decision will not affect your participation in Children of the 90s or any future NCSP testing you would like to do.

WHAT IS NCSP?

NCSP is an NHS sexual health programme. Its aims are to raise awareness about the effects of chlamydia and gonorrhoea and to provide access to free and confidential testing services. More information about the NCSP can be found at www.chlamydia-screening.nhs.uk.

LUNG FUNCTION



WHY DO YOU WANT TO MEASURE MY LUNG FUNCTION?

We want to measure how much air you can blow from your lungs over a short period of time. This tells us how much air your lungs can hold and about the size of the passages (airways) that carry air to your lungs. We're interested in seeing how this changes as people get older and how it differs from one person to the next. For example, someone who has asthma now may not be able to blow as hard as they did when they were younger.

WHAT'S INVOLVED?

With a nose-clip on we will ask you will blow as hard as possible, for as long as you can, into a mouthpiece. We would like you to do this before and after inhaling a drug called salbutamol (Ventolin), which is used to treat asthma. You can choose not to have the salbutamol; we will then just ask you to blow into the mouthpiece once.

IS IT SAFE?

Salbutamol is very safe and should have no unpleasant side effects, although you may notice your heart beating faster for a short time after taking it.

WHAT WILL YOU DO WITH MY SAMPLES?

A lot of the research using your samples will take place in Bristol but some of your samples may be made available to researchers working in universities, hospitals or other organisations in the UK or abroad. We may ask for a 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 will not sell or make any profit from the samples or cell lines you donate and they will only be used in ethically approved research.

LIVER SCAN



WHY DO YOU WANT TO SCAN MY LIVER?

Fat in the liver can cause health problems in older people. We want to know whether having fat in the liver is common in young adults. We also want to measure liver fibrosis build-up. This is the scar tissue that builds up when the liver has been injured. We want to find out the reasons for this and whether it makes people ill now and as they get older. To do this, we want to do an ultrasound scan of your liver.

WHY DO I HAVE TO FAST?

Eating food affects how your liver looks on the scan, so we need to do the scan when you have 'fasted' (not had anything to eat or drink, except water) for at least six hours. We will do the scan near the start of your visit. This will be either immediately before or after your blood sample.

You can still have a liver scan even if you decide not to give blood.

WHAT'S INVOLVED?

You may be asked to change into a loose-fitting top (we will provide one if you have forgotten to bring your own). We have a private room where you can change. A member of staff will ask you to lie on a couch on your back. They will place some gel on your stomach, then place a probe over the gel and look at pictures of your liver on the scanner monitor (screen). The scan is painless, but during the scan you will feel a slight vibration on the skin at the tip of the probe.

IS IT SAFE?

Yes, although if you are pregnant, or think you might be, we will not ask you to do this scan. The scan uses sound waves, not X-rays or gamma-rays. Ultrasound scans have been used widely for over 30 years and there are no known risks. They are considered to be very safe.



HEART HEALTH

We want to find out how your lifestyle and health can affect your arteries and heart and how we can use this information to help prevent heart disease. We can see changes in the blood vessels long before we can see any evidence of heart disease.

We would like to do five types of arteries and heart tests throughout the day.

NECK SCAN (CAROTID ARTERIES)



WHY DO YOU WANT TO MEASURE MY NECK?

We want to take an ultrasound scan of the main blood vessels in your neck (carotid arteries). These are the arteries that transport blood to your brain. This scan measures how thick the walls of your arteries are. This allows us to collect information about the other arteries in your body and whether they are stiff or blocked.

WHAT'S INVOLVED?

A member of staff will ask you to lie on a couch, with your arms by your side. They will place some gel on your neck, then place a probe on the gel and look at pictures of your arteries and record them on the scanner screen. We will do this once on each side of your neck. This is a completely painless technique and only takes a few minutes.

IS IT SAFE?

Yes, although if you are pregnant or think you might be, we will not ask you to do this scan. The scanner uses ultrasound. Ultrasound scans have been used widely for over 30 years and there are no known risks. They are considered to be very safe.

HEART SCAN (ECHOCARDIOGRAPH)



WHY DO YOU WANT TO SCAN MY HEART?

To gather information about the structure and function of your heart.

WHAT'S INVOLVED?

Before your heart scan you will need to have fasted for at least two hours.

If you are wearing a shirt or a blouse, a member of staff will ask you to unbutton it to the waist. Otherwise they will ask you to change into a loose top. We have a private room where you can do this. Then they will ask you to rest on a couch for a few minutes before starting. This will allow your blood pressure and heart rate to settle.

Next they will ask you to lie on your left side while they attach sticky leads to your side and both shoulders. They will put some gel on your chest, then place an ultrasound probe on the gel and look at pictures of your heart beating on the scanner monitor (screen). They will look at your heart from two angles – the middle of your chest and lower down on your left side. They will keep your chest covered throughout the scan.

IS IT SAFE?

Yes, although if you are pregnant or think you might be, we will not ask you to do this scan. The echocardiography machine uses ultrasound. Ultrasound scans have been used widely for over 30 years and there are no known risks. They are considered to be very safe.

SKIN TEMPERATURE



We'd like to measure your skin temperature by asking you to hold a thermometer probe between your thumb and index finger for one minute.

BLOOD SPEED (PULSE WAVE VELOCITY)



WHY DO YOU WANT TO MEASURE HOW FAST MY BLOOD TRAVELS?

We'd like to do a test, called pulse wave velocity (PWV), to measure how elastic your arteries are. We do this by measuring the speed your pulse moves round your body. A member of staff will place cuffs (like blood-pressure cuffs) around your thigh and neck and blow air into the cuffs for a few minutes. They will then measure and calculate how long it takes for the pulse wave to travel between two recording points.

IS IT SAFE?

Yes, but you may experience a small amount of discomfort for a few minutes when the cuffs are inflated.

ACTIVITY MONITOR



WHY DO YOU WANT TO MEASURE HOW ACTIVE I AM?

We would like to see how your activity levels affect your heart and how they compare to other people in Children of the 90s.

WHAT'S INVOLVED?

We will ask you to wear a small device either around your waist or on your wrist. This will record when you are active and inactive. We would like you to wear the monitor constantly for four days, including when you are asleep. You only need to take it off a) for a bath/shower, b) if swimming c) if taking part in physical exercise that could damage the monitor, e.g. kick-boxing, or d) if it could hinder your activity. We will also give you an activity log to fill in.

After four days, please put the device in the pre-paid envelope provided and post it back to us.

BLOOD PRESSURE AND PULSE



WHY DO YOU WANT TO MEASURE MY BLOOD PRESSURE AND PULSE?

As people get older their blood pressure can increase. We know that if a person has high blood pressure over many years and it is not detected or treated it can lead to problems in later life.

WHAT'S INVOLVED?

We will measure your blood pressure in different ways while you are sitting, standing and exercising. When you are seated, we will place a cuff around your upper arm. The cuff will inflate (fill with air) for a moment and then deflate (release the air). The machine will immediately show your blood pressure reading.

We will then ask you to do a simple step test and handgrip test. The step test will take only two minutes and is a light exercise test.

We will also measure your central blood pressure. That is the pressure in the large artery (aorta) which the heart pumps blood into. We will place a small pencil-shaped device on the pulse points on your wrist.

IS IT SAFE?

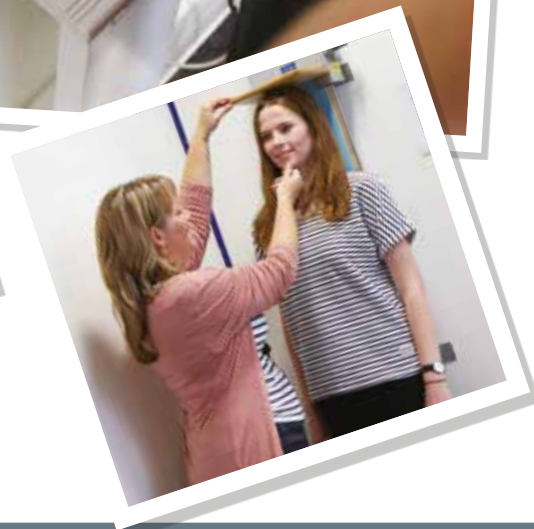
There are no risks involved, although the blood-pressure cuff around your upper arm might feel a little tight and uncomfortable for a moment.





BODY SIZE AND SHAPE

We will measure your weight, height (standing and seated), waist, arm and hip size.



DEXA SCAN

WHY DO YOU WANT TO SCAN MY BODY?

We do this to measure your muscles, body fat and bones.

WHAT'S INVOLVED?

A member of staff will ask you to lie on a scanner and stay very still. The machine's arm will pass over you twice; first to scan your whole body, second to scan your hip in more detail.

WHAT EXACTLY IS A DEXA SCAN?

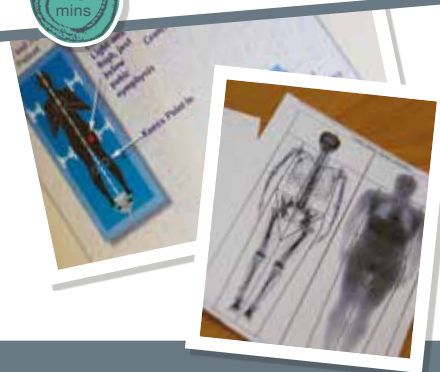
A DEXA scanner is a large scanning machine that measures the amount of calcium and other minerals in your bones. The result is called the 'bone mineral density'. Denser bones have more calcium and minerals. They are stronger and less likely to break.

IS IT SAFE?

Yes, although if you are pregnant or think you might be, we will not ask you to do this scan even though risk assessments have shown that there is no risk to unborn babies. DEXA scans use a much lower level of radiation than X-rays and less than the amount we are exposed to in our daily lives.

IS THERE ANYTHING ELSE I NEED TO KNOW?

Please do not wear clothes with metal fastenings and remove watches, earrings, body piercings and other metal objects for the scan if possible, as these can interfere with the result.



3D WHOLE-BODY SCAN



WHY DO YOU WANT TO DO A 3D SCAN OF MY BODY?

We do this to gather extra information about your size, shape and posture. We do it using a three-dimensional (3D) machine that uses light scanners and computer software.

WHAT'S INVOLVED?

For this scan, we'd like you to stand in a private scanner (it's a bit like a large photo booth) inside a private room. This is best done without any clothes on and there is a private curtained cubicle in the room where you can undress. If you prefer, you can wear flesh-coloured or light-grey underwear (bras without underwire) for the scan. If you would be more comfortable with this option, please wear flesh-coloured or light-grey underwear on the day.

IS IT SAFE?

Yes, this scan is safe for everyone. The image is produced by light scanners and computer software. There is no X-ray or radiation involved.



PLAYING YOUR PART

In recent years we have sent you a 'play your part' pack. It explained your role in Children of the 90s now you are an adult. It also asked whether you would allow us to use your health (NHS) and other official records (education, benefits, earnings and any criminal conviction or caution records you may have).

Well over 4,000 participants filled in the form and let us know their decision about these questions.

If you haven't sent back your form yet, then we will discuss this with you during your Focus visit and ask you to complete the consent form. We will ask:

1. If you are happy, or not, to carry on taking part in Children of the 90s as an adult?
2. If you are happy, or not, for Children of the 90s to extract and then use your health and routine records in our research?

You are free to make your own decisions about these questions, and to make a separate decision about each type of record.

If you'd like to look at the pack in advance, you can download it here:

<http://www.childrenofthe90s.ac.uk/participants/playingyourpart/>

Otherwise we'll give you a pack when you come for your Focus visit. Please call us on 0117 331 0010 if you'd like us to post a pack to you or if you would like to discuss any aspect of 'play your part' before your visit.



INTERVIEW AND COMPUTER TASKS

WHAT'S INVOLVED?

This session involves interviews, computer tasks and questionnaires. Together they will tell us about the way you feel and how you react to people around you. If you have participated in a Focus visit before, we want to find out how you may have changed since your last visit. We only include questions and tasks that have been tested and approved for use in research. You may find some questions a bit sensitive but, like everything else in Children of the 90s, you choose whether you want to do all or only some parts of this session.

There are six stages to this session.

1. Unusual experiences interview

We will ask you some questions to find out about any unusual experiences or events that you may have experienced.



4. Cognitive function interview

We will ask you questions to check your memory function.



2. Moods and feelings computerised questionnaire

We would like to ask you some questions about your moods, how you feel, and how you act in certain situations.



5. Alcohol, tobacco and other drug use questionnaire

We will ask you a series of questions about your alcohol, tobacco and other drug use.



3. Computerised cognitive tasks

We will ask you to complete some short computer tasks looking at decision making, emotion recognition and memory.



6. Reproductive health questionnaire

We will ask female participants some additional questions about their periods and pregnancy.



WHAT ELSE DO I NEED TO KNOW ABOUT THE INTERVIEW AND COMPUTER TASKS SESSION?

With your written consent, some of your interviews may be recorded for data quality and training purposes. All the answers you give will be completely confidential and no researcher will be able to link your answers back to you.

If you are worried about any of the issues in these sessions, we can tell you how to contact people who can give you help and advice. If there is a really serious problem which puts you at risk and you have not been able to talk to anyone about it, we will discuss this with one of the doctors who work with us who may be able to help you.

ARE THERE ANY ADVANTAGES TO TAKING PART IN FOCUS@24+?

EXPENSES

We will cover your travel expenses and also provide you with a £40 shopping voucher to compensate you for your time.

TEST RESULTS

Unlike a health check with your doctor, everything you do during your Focus visit is purely to assist us with health research. However, some of the things we do might indicate increased risk for some health problems (see the **test results** section). If you have given us written consent to tell you the results of these tests, we will do so and give you a letter to take to your GP. Other tests we do are useful for research but the results have no clear medical meaning at the moment. Therefore we will not tell you about those results.

If we do not contact you with any results, this does not necessarily mean that you have a clean bill of health. If you have any symptoms that cause you concern you should always contact your GP in the first instance.

ARE THERE ANY DISADVANTAGES TO TAKING PART?

TIME

Other than giving up your time to attend, there are no major disadvantages in taking part.

FASTING

We need you to come to the visit having 'fasted' for the blood sample, i.e. having nothing to eat or drink (except water) in the previous six hours. After you've had something to eat, we may need to ask you to fast for another two hours before having a heart scan.

GIVING BLOOD

You may have a small bruise where the blood was taken. This will clear within a couple of days. There is a slight risk that you may feel faint during or after giving blood. Our staff are trained to look after you if this happens.

BLOOD PRESSURE

You may experience a small amount of pressure on your arm when the cuff is inflated (filled with air). This only lasts a few seconds.

PREGNANCY

If you are pregnant or think you might be, we will not do the DEXA, liver or heart scans. All the other tests we will undertake are safe and are conducted by trained staff.

LUNG FUNCTION

There is a small risk that your heart might beat faster for a short while after inhaling the asthma drug salbutamol (Ventolin).

BLOOD SPEED

You may experience a small amount of discomfort when the cuff is inflated (filled with air). This lasts a few minutes.

TEST RESULTS

We will give you feedback about the following tests if you have given us written consent to do so:

- If your **blood pressure** is high we will tell you during your Focus visit. We will also give you a letter to take to your GP so that they can test this again, discuss it with you, and do further tests if necessary.
- If you have **high blood sugar** (an indicator of diabetes) or **high levels of total cholesterol**, we will send you a letter for yourself and another one to take to your GP.
- If either your **liver scan** result or **liver function** blood test result is higher than normal, we will send you a letter for yourself and a second one for your GP. Your GP might suggest further tests or lifestyle changes.
- We do a number of blood tests called **full blood count (FBC)**. If your **haemoglobin (Hb)** is low (risk of anaemia) or high (could mean your blood flows too slowly), we will send you a letter. We will also write to you if your **white blood cells (WBC)**, which fight infection, or your **platelet count (PC)** – the cells that help your blood clot – are outside the normal range.

When will I hear from you?

- We will tell you your best **lung function** result during your visit. If your test result is lower than normal we will write to you **within three months**.
- For **blood sugar, cholesterol and liver function**, the samples are sent away in batches for testing. Therefore it could be **up to 12 months** before we contact you with the results if they are outside the normal range.
- For the **liver scan**, if your result is higher than normal we will write to you **within three months**.
- For **FBC**, if your results are outside the normal range we will contact you **within four weeks**. If the test results show you may be seriously unwell, we will contact you **as soon as possible**.

There is a small chance you may find some of the test results upsetting but we will discuss this with you during your Focus visit.

WILL MY GP BE INVOLVED?

We will not routinely inform your GP that you are a participant in Children of the 90s or what tests you have had. However, if certain test results (see the **test results** section) are outside the normal range and you have given us written consent to tell you the results, we will give you a letter to pass on to your GP. This letter will tell your GP that you are in Children of the 90s and provide them with the test results.

DOES ATTENDING FOCUS@24+ COMMIT ME TO DOING OTHER ACTIVITIES WITH CHILDREN OF THE 90S IN THE FUTURE?

No. You can decide at any time whether you want to take part or not. If you would like us to stop contacting you completely, you just need to let us know and we will respect that wish.

CONFIDENTIALITY AND DATA PROTECTION

Any data we collect from you will be stored with an individual ID number but with no personal information (your name, address or date of birth) attached. Files that link this ID number to your personal details will be securely stored. The data will be used for research purposes only and will be analysed by Children of the 90s approved researchers. None of these researchers will have access to your personal information.



WHO HAS ORGANISED FOCUS@24+?

Children of the 90s. The scientific and executive directors for the Focus@24+ visit are:

- Professor Paul Burton
- Professor George Davey Smith
- Ms Lynn Molloy

WHO HAS FUNDED FOCUS@24+?

- The Medical Research Council (MRC)
- The Wellcome Trust
- The University of Bristol
- Alcohol Research UK
- The British Heart Foundation

WHO HAS REVIEWED AND APPROVED THE RESEARCH?

- Anonymous reviewers for the MRC and the Wellcome Trust
- Grant board members of the MRC and the Wellcome Trust
- The Children of the 90s Executive Committee
- The Children of the 90s Original Cohort Advisory Panel (OCAP)

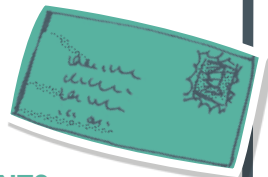
In addition, all research connected to the NHS is looked at by an independent group of people, called a Research Ethics Committee. Their role is to protect your safety, rights, wellbeing and dignity. In this case, the research has been reviewed and approved by:

- The Children of the 90s Ethics and Law Committee
- The Bristol Frenchay NHS Research Ethics Committee

WHO DO I CONTACT IF I HAVE ANY QUESTIONS OR CONCERNS OR NEED MORE INFORMATION?

Speak to any member of staff when you attend who will do their best to answer your questions. You can also contact the visit team or the Children of the 90s Executive Committee.

- Tel: 0117 331 0010
- Email: info@childrenofthe90s.ac.uk
- Web: www.childrenofthe90s.ac.uk



WHO DO I CONTACT IF I WANT TO MAKE A COMPLAINT?

Deputy Executive Director
Children of the 90s
ALSPAC
Oakfield House
Oakfield Grove
Bristol BS8 2BN

Telephone: 0117 331 0010

Email: info@childrenofthe90s.ac.uk

Website: childrenofthe90s.ac.uk

Thank you for taking the time to read about your Focus @24+ visit and for your ongoing support of



Children of the 90s, Oakfield House,
Oakfield Grove, Bristol, BS8 2BN



0117 331 0010



info@childrenofthe90s.ac.uk



www.childrenofthe90s.ac.uk



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instagram.com/children_of_the_90s

**HAVE ANY OF YOUR DETAILS CHANGED?
NEED MORE INFORMATION?**

Please get in touch!



Scan this QR code
to go straight to
our website

V3 February 2016



Avon Longitudinal Study
of Parents and Children





Consent Form



We would like to ask you to undertake all of the following measurements/procedures. Please cross the "yes" box and initial to indicate that you give consent or cross the "no" box and initial if you do not consent. Please also cross and initial to indicate whether you would like us to inform you of the result, and give you a letter to give to your GP, if the tests marked * give cause for concern.

Consent Session 1		
General Consents	Cross	Initials
I confirm that I have read and understood the information sheet dated for this Focus visit. I have had the opportunity to consider the information and ask questions and I have had these answered satisfactorily.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason, without my legal rights being affected.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
I agree to participate in this Focus visit	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
I agree to my data being stored after completion of the Focus visit for use in other studies	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>

Consent for individual assessments (cross box and initial to give consent)	Consent to test		Consent to inform	
	Cross	Initials	Cross	Initials
Full body and hip DXA scans of bone density, fat and muscle mass	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>		
Weight, height, waist, hip and arm circumference	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>		
Seated and standing blood pressure* and pulse pressure	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
Central blood pressure (PWA)	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>		
3D body scan	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>		
Liver scan*	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
Lung function assessment*	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>



Avon Longitudinal Study of Parents and Children

Please turn over

Participant Consent Form
Focus 24+ v6 01/04/2017

Oakfield House
Oakfield Grove, Bristol
BS8 2BN, UK

T +44 (0)117 331 0010
E info@childrenofthe90s.ac.uk
W childrenofthe90s.ac.uk
5665

The University of Bristol holds legal liability insurance in the event that any participant is injured due to any negligence on the part of the University.

Permission for Samples Collection and Blood Tests	Cross	Initial
I agree to provide the following samples for this Focus visit (individually consented below). The purposes and possible risks of donating these samples have been explained to me. I understand that donated samples will be considered a gift but I will have the right to withdraw permission for analysis.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
I understand that my samples, including the main stocks of any genetic material collected such as DNA and RNA, will be stored in Bristol Bioresource Laboratories, University of Bristol. I understand that any of my samples (with an anonymous number only), or any information obtained from them including the sequence of my genetic material, may be sent to specialist research laboratories in the UK and abroad for analyses and the results returned to Children of the 90s. Researchers at these laboratories have no access to personal information about study participants.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>

Individual Samples and Blood Tests (cross box and initial to give consent)	Consent to test		Consent to inform	
	Cross	Initial	Cross	Initial
Individual Samples				
Blood Sample	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>		
Urine Sample	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>		
Saliva sample for DNA (if you do not wish to give a blood sample)	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>		
Individual Blood Tests				
Glucose (sugar)*	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
Lipids (form of cholesterol)*	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
Liver function*	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
Full blood count*	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
Hormones	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>		
Future Use				
I agree to my samples being stored after completion of the Focus visit for use in future genetic studies.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>		
I agree to my samples being stored after completion of the Focus visit for use in future non-genetic studies.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>		
I agree to cell lines produced from my samples being stored and used at any time in the future.	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>		

Participant Signature	<input type="text"/>	Date signed	<input type="text"/> / <input type="text"/> / <input type="text"/> 201
Initial	<input type="text"/>	Last Name	<input type="text"/>
Fieldworker Signature	<input type="text"/>	Date signed	<input type="text"/> / <input type="text"/> / <input type="text"/> 201
Initial	<input type="text"/>	Last Name	<input type="text"/>



Consent Form (continued)

We would like to ask you to undertake all of the following measurements/procedures. Please cross the "yes" box and initial to indicate that you give consent or cross the "no" box and initial if you do not consent.

Consent Session 2		
Consent for Individual Assessments (cross box and initial to give consent)	Cross	Initial
Computerised cognitive tasks	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
Cognitive function interview (some interviews will be recorded for data quality purposes)	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
Alcohol, tobacco and other drug use questionnaire	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
Unusual experiences interview (PLIKSi) (some interviews will be recorded for data quality purposes)	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>
Computerised questionnaire (moods and feelings, reproductive health [females only])	Yes <input type="checkbox"/> No <input type="checkbox"/>	<input type="text"/>

Participant Signature	<input type="text"/>	Date signed	<input type="text"/>	/	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Initial	<input type="text"/>	Last Name	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Fieldworker Signature	<input type="text"/>	Date signed	<input type="text"/>	/	<input type="text"/>	/	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>
Initial	<input type="text"/>	Last Name	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>	<input type="text"/>



Avon Longitudinal Study of Parents and Children

Participant Consent Form
Focus 24+ v6 01/04/2017

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Understanding Asthma study

Participant Information Sheet



We'd like you to take part in a new research study on asthma. This is a Children of the 90s research study that is also part of a worldwide study taking place in Brazil, Ecuador, New Zealand and Uganda. This study is hoping to understand the different causes of asthma around the world, in richer and poorer countries.

This leaflet explains what we would like you to do and why. Please read it as it will help you decide whether you wish to take part. Before deciding, you can ask us questions about it by calling us on 0117 331 0010 or emailing info@childrenofthe90s.ac.uk.

What is the purpose of the research?

There are many unanswered questions about what causes asthma and how it works. Whilst asthma can be managed successfully, current treatments don't work for up to half of asthma patients. We think this may be because, for some people with asthma, something is affecting how their nervous system controls their airways.

We want to look at these mechanisms as well as risk factors such as stress. Answering these questions will help us and other asthma researchers develop effective ways to prevent asthma and contribute to improved treatments for all people with asthma.

Why have I been invited to take part?

You do not need to have asthma to take part. We are interested in people who do not have asthma as well as those that do. By looking at both groups of people we can compare the differences between them.

You have been invited to take part because you attended the Focus@24+ clinic and completed a lung function test, or you may have reported that you have asthma in a Children of the 90s questionnaire or at a previous clinic.

What will I have to do?

Attend a 2 hour clinic at Clinical Research and Imaging Centre Bristol (CRICBristol), University of Bristol, 60 St Michael's Hill, Bristol BS2 8DX at a time that is convenient for you. The visit will involve a series of measures which are outlined below.

We might also invite you to a second (shorter) visit three months after your first one where we will repeat the blood pressure, sputum induction, nasal lavage, FeNO and TremoFlotests, and the questionnaire (see below). This is just to make sure that the measures we have taken are accurate, and has nothing to do with your health or the results from your first visit.

1. **Complete a short questionnaire.** We will ask you some questions about your lung health and home environment
2. **Skin prick allergy test on the arm.** We will put ten small drops of liquid allergen on your forearm and then prick each drop to see if you have a positive reaction. This is almost painless and just enough to break your skin. We will be testing for allergies to house dust mite, tree and grass pollen, cat and dog hair and three types of bacteria. You may take part even if you already know that you have an allergy to one or more of the test allergens. If any of the results are positive you may experience some itching, like a nettle sting, on your forearm. Other adverse reactions to skin prick testing are extremely rare. You will receive the results of your skin prick test at your visit.

Ideally, we would like you to avoid using antihistamines (usually used to treat allergic reactions) in the 5 days before your visit, as they can affect the skin prick test result. Of course, if you do need to use an antihistamine please do so but let us know on the day of your appointment.

3. **Blood pressure measurement.** We will measure your blood pressure twice while you are sitting down by placing a cuff around your upper arm. The cuff will inflate (blow up) for a moment and then deflate (let out the air) slowly. There are no risks involved, although the cuff may feel a little tight and uncomfortable for a moment.

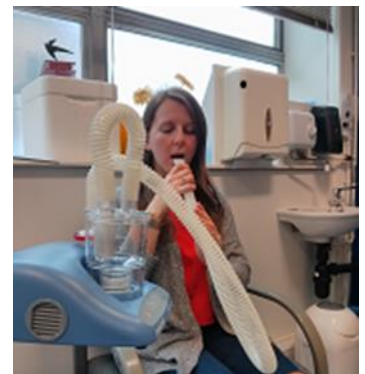
4. **Lung function test.** This will involve blowing into a special machine as hard as you can for a few seconds. You may feel breathless for a short period, although generally this test causes no discomfort. We may ask you to do this again after inhaling a common asthma drug called salbutamol. This is very safe and usually used to treat asthma. If you have recently attended Focus@24+ you will have already completed a lung function test and may not be asked to do it again.



Lung function test in progress

FOR ASTHMATICS ONLY: Using an asthma inhaler before your visit. If you use an asthma reliever inhaler (taken when wheezy, such as Ventolin) we would like you to stop using it for at least six hours before your visit. If you use an asthma preventer inhaler (usually taken every day whether wheezy or not) we would like you to stop using it for at least 12 hours before your visit. This includes long-acting bronchodilators such as salmeterol (Serevent) and formoterol (Oxis). If you use a long acting oral treatment, known as theophyllines, usually taken in the form of a daily or twice daily tablet e.g. Austyn, Neulin, Siobid or Theo-Dur please stop taking this treatment 24 hours before your visit. However, if you have an asthma attack or are short of breath you should use your inhaler as normal and please let the Research Nurse know when you come in. If you are unsure of your inhaler type please contact us and we will be able to advise you. If you are on medication, please bring it with you to the clinic.

5. **Sputum induction test.** This test involves inhaling salbutamol, then breathing in a fine spray of saline solution (slightly salty water). After a few minutes of breathing the spray, you may cough and we will collect what you cough up (sputum) and analyse it. Depending on how much you cough up, we may ask you to do this just once or several times, for no more than 16 minutes in total. This may feel a bit like having a cough or cold.



Sputum induction test in progress

Doing this may irritate the back of your throat and affect your breathing. If this happens, we will ask you to inhale some salbutamol again. A trained nurse will do this test and monitor your breathing carefully throughout.

6. **Nasal lavage sample.** We will spray a fine mist of saline solution (slightly salty water) into your nostril through the end of a syringe, then we will ask you to tip your head forward to blow the solution out through your nose into a tube to collect the solution for analysis. This may feel a bit like getting water up your nose when swimming but is unlikely to cause any other discomfort.

If you use a steroidal nasal spray for an allergy e.g. hayfever or other reason (e.g. runny nose), we will ask you not to take this treatment for 7 days before your test. Nasal sprays include products containing beclometasone, budesonide, fluticasone, mometasone and triamcinolone. However, if you have a flare up of your allergy, please take your medication as usual and tell us when you visit the clinic.

Other treatments that may affect the research results are non-steroidal anti-inflammatories. These are usually used for conditions such as headaches, painful periods, sprains and strains, colds and flu, arthritis, and other causes of long-term pain. Commonly used products are ibuprofen, naproxen, diclofenac and celecoxib. **We ask that you do not take any non-steroidal anti-inflammatories for 6 hours before your visit.** However, if you need to use a non-steroidal anti-inflammatory in the 6 hours before your visit, please do so and tell us on the day.



Left: Nasal lavage in progress

Right: The syringe and atomiser used in nasal lavage



7. Blood sample. We will take a small blood sample from your arm and use it to check the levels of proteins that can cause your airways to get inflamed. We will also count the number of red cells, white cells and platelets in your blood. You might find this slightly uncomfortable and your arm may have a temporary bruise. You can eat and drink as normal before giving blood.

8. FeNO (fractional exhaled nitric oxide) test. This test involves you breathing in as deeply as you can through a special mouthpiece attached to a machine and then slowly breathing out into the machine at a constant rate. You may feel breathless for a very short period, although generally this test causes no discomfort. We will ask you to do this twice. This test provides a measure of allergic inflammation in the air passages of the lungs. There are no risks or side effects from doing the test.



FeNO measure in progress

9. TremoFlo (airwave oscillometry system) test. This test involves breathing as normally as possible into a special machine for at least 16 seconds. When you breathe the machine will pass tiny airway vibrations into your airways, which feels

like a flutter. We will ask you to do this test three times. There are no risks or side effects from doing the test. TremoFlo measures natural resistance to air flow in different parts of your lung and is another measure of lung function.



TremoFlo measure in progress

Please note: You can stop any of the tests at any time.

What will you do with my samples?

We will measure the number of cells in your sputum, nasal lavage and blood samples, and measure them for chemicals naturally produced by the body in response to inflammation. We will also extract genetic material from your samples. These will be used for genetic studies and epigenetic analysis, for example, to see if DNA from your sputum (taken from the lung) works differently to DNA from your blood. We will also be storing samples for future use if you agree to this.

Am I eligible to take part?

You will not be able to take part if:

- You have had lung or chest problems or diagnoses, colds, or hospital admissions in the past four weeks
- You are taking long-term medication (other than for asthma)
- You have a history of chronic lung or chest disease (other than asthma) or heart disease (including high blood pressure)
- You are pregnant
- You have had an acute asthma attack which required an increase in your usual treatment in the past four weeks

If you are unsure if you are eligible but wish to take part please write this on the reply slip and we will get in touch. For example, we may be able to reschedule your appointment if you have been unwell.

Do I have to take part?

No - it is up to you to decide whether to take part. If you decide to take part, you can withdraw from the research at any time and you can choose to take part in the first visit but not the second one. If you decide not to take part it will not affect any other Children of the 90s activities that you or your family may be involved in.

Where will it take place?

CRIC Bristol, University of Bristol, 60 St Michael's Hill, Bristol BS2 8DX

How long will it take?

The first clinic visit should last about an 2 hours. If you are invited for the second visit it should take about an hour and a half.

Will I receive anything for my time?

As a thank you we will offer you £20 in shopping vouchers for your first clinic and £10 for the second (shorter) one. We will also reimburse your travel and accommodation expenses and can provide a taxi to CRIC Bristol or free parking at Children of the 90s (a 10-15 minute walk from CRIC), if required.

Are there any benefits to me if I take part?

There are no direct health benefits to you for taking part, and this is not a health check; we are asking you to help us with research that could help people in the future. If you have any symptoms that cause you concern at any time, you should always contact your GP.

You will have the option to receive results for the skin prick allergy test. With your consent, we will give you a letter to take to your GP about the skin prick allergy test results if you had an allergic reaction.

If your blood pressure is higher than normal, we will give you a letter to take to your GP.

If you do not currently have asthma and the lung function test gives cause for concern, and if you have given us consent to do so, we will contact you and then send you a letter to give to your GP within three months of your visit. If you have asthma we will not contact you or send you a letter for your GP as you will already have had a diagnosis.

If your FeNO tests shows that your lungs may be inflamed, we will give you a letter to take to your doctor.

If the cell count in your blood shows that you may have a serious health issue we will contact you as soon as possible, usually within a few days of your clinic visit. We will only do this if you have given us consent to do so.

Are there any risks or disadvantages if I take part?

We have outlined the low-level risks associated with each of the tests above. There are also some side effects of the drug salbutamol used as part of the lung function and sputum induction tests. However, the side effects with the dose used are rare. The most common of these is a mild tremor (which affects fewer than 1 in 100 people). Other side effects can be anxiety, headache, muscle cramps, dry

mouth and palpitations. These usually only occur in higher doses or after repeat use. These occur in fewer than 1 in 1000 people. Other than your time, there are no anticipated disadvantages in taking part.

What do I have to do now?

If you want to take part, please complete the enclosed reply slip and return it to us in the freepost envelope provided. Alternatively, call or email using the contact details over the page. If you don't want to take part please let us know so we don't send you any more reminders about this study.

Confidentiality and data protection

Your information will be stored with an individual ID number but not with your personal information attached (such as your name, address or date of birth). Files that link this ID number to your personal details will be securely stored and only a restricted number of Children of the 90s staff will have access to them. The data will be used for research purposes only and will be analysed by Children of the 90s approved researchers. None of these researchers will have access to your personal information.

A lot of the research using your samples will take place in Bristol but some of your samples may be made available to researchers working in universities, hospitals or other organisations in the UK or abroad. We may ask for a 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 will not sell or make any profit from the samples you donate and they will only be used in ethically approved research.

The results of the study will be published in scientific journals and a summary of the results will be provided to all study participants. No individual information or names will be published.

What if something goes wrong? What if I have questions or concerns?

As with all Children of the 90s studies, the University has legal liability insurance in the unlikely event that any participant is injured due to negligence on the part of the University or its employees. If you have questions or concerns about any aspect of this research, please contact Children of the 90s (0117 331 0010, info@childrenofthe90s.ac.uk). If we are unable to answer your question or concern directly we will talk to the lead researcher and get back to you as soon as possible.

Who is organising and funding the research?

This research is organised by Children of the 90s. Professor Neil Pearce, London School of Hygiene and Tropical Medicine, is overseeing the project worldwide. Professor John Henderson is the lead researcher at Children of the 90s.

The research has been funded by the European Research Council. In addition, Children of the 90s receives core funding from the Wellcome Trust, the UK Medical Research Council and the University of Bristol.

Who has reviewed this research?

- Anonymous reviewers and grant board members for the European Research Council
- Children of the 90s executive committee
- Children of the 90s ethics and law committee (ALEC)
- Children of the 90s original cohort advisory panel (OCAP)
- An NHS Research Ethics Committee.

Contact for further information

Tel: **0117 331 0010** Email **info@childrenofthe90s.ac.uk**

**Thank you for taking the time to read about our asthma research
and for your ongoing support of Children of the 90s.**



Understanding Asthma study

Visit 1 consent form

We would like to ask you to take part in all of the following measurements/procedures. Please cross the “Yes” box and initial to indicate that you give consent or cross the “No” box and initial if you do not consent. For tests marked * please also cross and initial to indicate whether you would like us to inform you of the results, and give you a letter to give to your GP if the test results give cause for concern.

General consents		Cross box		Initial	
I confirm that I have read and understood the information sheet Understanding Asthma study v5 dated 24 March 2017. I have had the opportunity to consider the information and ask questions and I have had these answered satisfactorily.		Yes <input type="checkbox"/>	No <input type="checkbox"/>		
I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason, without my legal rights being affected.		Yes <input type="checkbox"/>	No <input type="checkbox"/>		
I agree to participate in this study		Yes <input type="checkbox"/>	No <input type="checkbox"/>		
I agree to my data being stored after completion of the study for use in other studies		Yes <input type="checkbox"/>	No <input type="checkbox"/>		
Consent for individual assessments (cross box and initial to give consent)		Consent to test		Consent to inform	
		Cross	Initial	Cross	Initial
a)	Seated blood pressure*	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
b)	Lung function tests* (feedback for non-asthmatic participants only)	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
c)	Skin prick tests*	Yes <input type="checkbox"/>	No <input type="checkbox"/>	Yes <input type="checkbox"/>	No <input type="checkbox"/>
d)	Lung function and asthma questionnaire	Yes <input type="checkbox"/>	No <input type="checkbox"/>		
Permission for samples collection and blood tests				Cross box	Initial
I agree to provide the following samples (individually consented below). The purposes and possible risks of donating these samples have been explained to me. I understand that donated samples will be considered a gift but I will have the right to withdraw permission for analysis.				Yes <input type="checkbox"/>	No <input type="checkbox"/>
I understand that my samples, including the main stocks of any genetic material collected such as DNA and RNA, will be stored in Bristol. I understand that any of my samples (with an anonymous number only), or any information obtained from them including the sequence of my genetic material, may be sent to specialist research laboratories in the UK and abroad for analyses and the results returned to Children of the 90s. Researchers at these laboratories have no access to personal information about study participants.				Yes <input type="checkbox"/>	No <input type="checkbox"/>
Individual samples and blood tests (cross box and initial to give consent)		Consent to test		Consent to inform	
		Cross box	Initial	Cross box	Initial
Individual samples					



Participant Information Sheet

Understanding eczema

We'd like you to take part in a new research study. We want to understand more about the different types of eczema so that treatments can be improved.

What is the purpose of the research?

There are many unanswered questions about what causes eczema and how it works. Although eczema can be managed successfully for some people, we want to find out why certain treatments don't work for others. We think this is because there are different types of eczema. As well as looking at the various types of eczema, we want to look at people's general health and their environment. This will help us develop effective ways to prevent eczema and contribute to improved treatment options.

Why have I been invited to take part?

You have been invited to take part because you are a participant in Children of the 90s.

You do not need to have eczema to take part. We are interested in people who do not have eczema and those that do. By looking at both groups of people we can compare the differences between them.

What will I have to do?

Come to a 100-minute clinic at Children of the 90s at a time that is convenient for you. During your visit we will do a series of tests. We explain these below.

1. **Complete a short questionnaire.** We will ask you some questions about your general health, allergies and eczema (if you have it).
2. **Full body skin examination.** In a private area, we will ask you to undress to your underwear (or to a level that you are comfortable with). Gowns will be provided for you to change into. The Research Nurse will examine your skin to check whether you have eczema on your body and, if you do, assess how severe it is. The research nurse may feel your skin texture on the outer part of your upper arms, or in areas where you have thickened areas of eczema to assess its texture. We will offer a male or female chaperone for this examination.
3. **Skin swab.** We will lightly rub your skin but won't cut or puncture it. A small rubber cup will be placed next to your skin and approximately half of a teaspoon of clear neutral solution will be placed into the cup on your skin. The area inside the cup is then rubbed with a rounded tipped rod 20 times and the solution is then removed from the tube. This won't harm your skin. The sample will be taken from an area of inflamed skin (if you have eczema), and an area of non-inflamed skin. If you do not have eczema only one sample will be taken. Both samples will be taken from near where you will have the skin biopsy (lower back). This will be done just before we perform the skin biopsy.



Skin swab being performed

We will ask you to only use Dove soap for a period of 7 days prior to this test. We will also ask you to stop using topical treatments (except for emollients) at the site of the skin swab / biopsies (on the lower back) for 14 days beforehand. If you bring your receipt to the visit, we will reimburse the cost of the soap.

4. **Skin biopsy.** We will remove two very small pieces of your skin, each about 2mm in size. This is about the size of a pencil point.

Before we take the biopsies we will take two seated blood pressure readings. Whilst you are seated we will place a cuff around your upper arm. The cuff will slowly inflate and then the cuff slowly deflates. The machine will immediately show your blood pressure reading. We will also measure your weight.

We will normally take both pieces of skin from your lower back, one from the left side and one from the right side. We will clean the area first, then give an injection of local anaesthetic at each site. Each biopsy will be done individually, so if after the first biopsy you do not wish to have the second biopsy taken, you will be able to decline this.

After we've removed the two pieces of skin, we'll cover the areas with dressings and if necessary will stitch the areas, although most people will not need this. We will cover the wounds with dressings and these will need to be kept dry for 24-48 hours to make sure they stay in place. The dressings on your lower back may be difficult to reach, so you may find it helpful to have a friend or relative assist you to remove the dressings. The procedure may leave very small permanent scars which may be a different colour to the rest of your skin. In very rare cases, your scars may be slightly raised, if you are prone to scarring.

We will give you an aftercare leaflet to take away with you.

5. **Blood sample.** We will take a small blood sample from your arm. You can eat and drink as normal before giving blood.

Please note you can stop any of these tests at any time.

What will you do with my samples?

With the skin swab we will be looking at the bacteria on your skin, known as the microbiome. There are good and bad bacteria on our skin which can influence our health. We want to look to see if there are differences in the microbiome between inflamed and non-inflamed skin.

We will ask you if we can keep the biopsy samples for future studies of epigenetics and gene expression in the skin. Epigenetics is the study of biological mechanisms that switch genes on and off. Gene expression is the process by which the information contained within a gene becomes a functional product such as protein or RNA.

From your blood we will be able to look closely into the different types of cells which are part of your immune system. This will allow us to investigate the role of the immune system in eczema.

We will use your blood sample to carry out a full blood count which looks at the number of red cells, white cells and platelets in your blood as well as the level of haemoglobin (which is a measure of anaemia). Your blood sample will also be used to look at proteins thought to be associated with eczema and, also, inflammation.

Will you use my blood sample for DNA and genetics?

Yes, with your consent we will extract DNA from your blood for genetic and epigenetic research. We will also extract RNA from your blood and skin biopsies for gene expression analysis. RNA carries out the instructions of DNA. Although we all have essentially the same genes, there are many small differences between us. Different versions of our genes can make us more likely or less likely to develop common diseases, such as eczema. Our research on genes has no clear medical meaning at the moment and therefore we will not tell you about these results.

How are the samples stored?

The samples are stored with unique ID numbers so that we can link your test results to other data about you.

Future research

A lot of the research using your samples will take place in Bristol but some of your samples may be made available to researchers working in universities, hospitals or other organisations in the UK or abroad. We may ask for a 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 will not sell or make any profit from the samples you donate and they will only be used in ethically approved research.

Your data will be used for research purposes only and will only be analysed by researchers who have been approved by the Children of the 90s executive committee. None of these researchers will have access to your personal information.

Linking your data – playing your part

In recent years we have sent you a 'play your part' pack. It explained your role in Children of the 90s now you are an adult. It also asked whether you would allow us to use your patient health information and other official records (education, benefits, earnings and any criminal conviction or caution records you may have). Well over 5,000 participants filled in the form and let us know their decision about these questions.

If you haven't sent back your form yet: then we will discuss this with you during your visit and ask you to complete the consent form. We will ask:

1. If you are happy, or not, to carry on taking part in Children of the 90s as an adult?
2. If you are happy, or not, for Children of the 90s to extract and then use your health and routine records in our research?

You are free to make your own decisions about these questions, and to make a separate decision about each type of record. If you'd like to look at the pack in advance, you can download it here: <http://www.childrenofthe90s.ac.uk/participants/playingyourpart/>

Otherwise we'll give you a pack when you come for your visit. Please call us on 0117 331 0010 if you'd like us to post a pack to you or if you would like to discuss any aspect of 'play your part' before your visit.

How your health data will be used in this research: most people visit their GP when seeking help for their eczema, although people with severe eczema may also seek care at a hospital or from other specialists (e.g. an eczema nurse). Understanding details about your care (for example when you visited the GP, the diagnosis the GP made and the drugs you were given) will help the researchers understand how severe your eczema is and how, for example, it has changed over time. Children of the 90s staff will link your patient health information with information you have given Children of the 90s (for example in questionnaires or at Focus clinics). The Children of the

90s will make sure your information is anonymised before making it available to the researchers in a secure research computer.

If you don't want your patient health information used in this study then please let us know. This will not affect any other part of your involvement in Children of the 90s.

If you let us know before the study starts, then we can exclude your records from the research. Once the research has started it will not be possible to exclude your records.

If you want to exclude your records please speak to a member of the Understanding Eczema staff on 0117 3310010 or, you can email us alspac-linkage@bristol.ac.uk, phone us on 0117 3310033 or write to us at Data Linkage Team, Children of the 90s, Oakfield House, Oakfield Grove, Bristol BS8 2BN.

Am I eligible to take part?

You will not be eligible to take part if you are pregnant, taking warfarin or other medications related to clotting diseases, if you have diagnosed, unstable heart disease, or if you have an allergy to local anaesthetics. Other medications which may prevent you from taking part include beta blockers, medication for an unstable heart condition or schizophrenia. Please check your current medications with us when you book an appointment.

Do I have to take part?

No – it is up to you to decide whether or not to take part. If you decide to take part, you can withdraw from the research at any time by contacting us at Children of the 90s using the contact details enclosed. Data or samples used in existing or past research cannot be recalled and it is necessary for us to retain some data for audit purposes. If you decide not to take part it will not affect any other Children of the 90s activities that you or your family may be involved in.

What should I wear?

Please come wearing loose clothing so we are able to take a skin swab and blood sample easily.

We will be checking your whole body for eczema and will ask you to undress to your underwear or a level you are comfortable with.

The biopsies will be taken from your lower back, so please wear clothing that makes this area easily accessible.

Where will it take place?

Children of the 90s, University of Bristol, Oakfield House, 15-23 Oakfield Grove, Bristol, BS8 2BN

How long will it take?

The visit should last about an hour and 40 minutes.

Will I receive anything for my time?

As a thank you we will offer you £20 in shopping vouchers. We will also reimburse your travel and accommodation expenses and can provide a taxi or free parking at Children of the 90s, if required. We will reimburse the cost of the Dove soap, if used.

Are there any benefits to me if I take part?

There are no direct health benefits to you for taking part, and this is not a health check; we are asking you to help us with research that could help with future treatment of eczema. If you have any symptoms that cause you concern at any time, you should always contact your GP.

We will do full blood count (FBC), which looks at the number of red cells, white cells and platelets in your blood as well as the level of haemoglobin (which is a measure of anaemia). If the test

results show you may be seriously unwell, we will contact you as soon as possible. We will only give you feedback about the test if you have given us written consent to do so.

We will take two seated blood pressure measurements. If the second of these measurements is higher than normal, with your consent, we will tell you and give you a letter to take to your GP so that they can test this again, discuss this with you, and do further tests if necessary.

Will my GP be involved?

We will not routinely inform your GP that you are a participant in Children of the 90s or what test you have had. However, if your blood test results show you may be seriously unwell and you have given us written consent to tell you the results, we will contact you to discuss the result and will, with your permission contact your GP as well. We will send you a letter confirming your results and also a letter will be sent to your GP telling them that you are a participant of Children of the 90s and providing them with the test results.

Are there any risks or disadvantages if I take part?

There are no serious risks involved in taking part. We have outlined some of the low-level risks associated with each of the tests below:

Blood sample: You might find this slightly uncomfortable and you might have a temporary bruise on your arm.

Injection of local anaesthetic: You might find this slightly uncomfortable and this may feel like a sting or a burning sensation. In rare cases (less than 1 in 100 people), people have an allergic reaction to the anaesthetic. If you know that you are allergic to local anaesthetic you will not be able to take part.

Skin biopsy: The scars should be tiny but are likely to last rather than being temporary. Usually the bit that hurts is the local anaesthetic injection (like an injection at the dentist) but some people may have some discomfort for a few days afterwards.

Potential risks of the skin biopsies include local discomfort, bleeding, bruising around the sites, and/or rarely, infection of the skin where the samples have been taken. In some cases this may require treatment with antibiotics. The procedure will leave two small scars (up to 2 mm, but the size may vary from person to person depending on their skin) and sometimes the areas may be more coloured, or a slightly different colour to the skin around it. In very rare cases there could be risks to 'keloid' formation, scar tissue that is red and raised, but this is highly unlikely with 2mm biopsies.

Using topical treatments before your visit - If you use topical treatments like creams or ointments (except for emollients) for eczema or other skin problems, we ask that you stop using this treatment in the area that we will take the biopsy from (lower back) for 14 days prior to your appointment. You would however be able to continue to use these treatments on other areas of your body. If you did need to use your treatment during this time, please contact us to re-arrange your appointment. Some examples of emollients are E45, Epaderm and Hydromol. Examples of topical treatments include hydrocortisone, Eumovate, Mometasone (Elocon) and Betnovate.

Using corticosteroids before your visit - Ideally, we would like you to avoid using oral corticosteroids in the 4 weeks before your visit, as they can affect the test results. Oral corticosteroids are used for treatment of eczema, asthma and allergies. Of course, if you did need to use an oral corticosteroid, you should do so and contact us to re-arrange your appointment.

What do I have to do now?

If you want to take part, please complete the enclosed reply slip and return it to us in the freepost envelope provided. Alternatively, call or email using the contact details over the page. If you don't

want to take part please let us know so we don't send you any more reminders about this study; you can find our contact details at the end of this information sheet.

Confidentiality and data protection

Any data we collect from you will be stored with an individual ID number but with no personal information (your name, address or date of birth) attached. Files that link this ID number to your personal details will be securely stored. As mentioned earlier, the data will be used for research purposes only and will only be analysed by researchers who have been approved by the Children of the 90s executive committee. None of these researchers will have access to your personal information. We will keep your personal details confidential and separate from your research data. Your personal details will not be shared with third parties except for certain service providers working on our behalf, for example VCars if you ask us to book a taxi for your visit.

Children of the 90s is compliant with GDPR (General Data Protection Regulation) and with the Data Protection Act (2018) with regard to the collection, processing, storage and disclosure of personal information. If you would like to find out more, please see our privacy notice here: <http://www.bristol.ac.uk/alspac/participants/privacy/>

The results of the study will be published in scientific journals and a summary of the results will be provided to all study participants. No individual information or names will be published.

What if something goes wrong? What if I have questions or concerns?

As with all Children of the 90s studies, the University has legal liability insurance in the unlikely event that any participant is injured due to negligence on the part of the University or its employees. If you have questions or concerns about any aspect of this research, please contact Children of the 90s (telephone 0117 331 0010, or email info@childrenofthe90s.ac.uk). If we are unable to answer your question or concern directly we will talk to the lead researcher and get back to you as soon as possible.

Who is organising and funding the research?

This research is organised by Children of the 90s. Dr Sinead Langan, London School of Hygiene and Tropical Medicine, is overseeing the project. Professor John Henderson is the lead researcher at Children of the 90s.

The research has been funded by the British Skin Foundation, the Wellcome Trust, and EU Horizon2020. In addition, Children of the 90s receives core funding from the Wellcome Trust, the UK Medical Research Council and the University of Bristol.

Who has reviewed this research?

- Children of the 90s executive committee
- Children of the 90s ethics and law committee (ALEC)
- Children of the 90s original cohort advisory panel (OCAP)
- A NHS Research Ethics Committee.

Contact for further information

Tel: 0117 331 0010 Email info@childrenofthe90s.ac.uk

**Thank you for taking the time to read about our eczema research
and for your ongoing support of Children of the 90s.**



Understanding eczema consent form

We would like to ask you to take part in all of the following measurements/procedures. Please cross the “Yes” box and initial to indicate that you give consent. Please cross the “No” box and initial if you do not consent. For tests marked * please also cross and initial to indicate whether you would like us to inform you of the results, and give you a letter to give to your GP if the test results give cause for concern.

General consents			Cross box	Initial		
I confirm that I have read and understood the information sheet Understanding eczema [Information sheet v4_25.09.2018.] I have had the opportunity to consider the information and ask questions and I have had these answered satisfactorily.			Yes No <input type="checkbox"/> <input type="checkbox"/>			
I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason, without my legal rights being affected.			Yes No <input type="checkbox"/> <input type="checkbox"/>			
I agree to participate in this study			Yes No <input type="checkbox"/> <input type="checkbox"/>			
I agree to my data being stored after completion of the study for use in other studies			Yes No <input type="checkbox"/> <input type="checkbox"/>			
Consent for individual assessments (cross box and initial to give consent)			Consent to test		Consent to inform	
			Cross	Initial	Cross	Initial
a)	Skin examination	Yes No <input type="checkbox"/> <input type="checkbox"/>				
b)	Presence of a chaperone during skin examination	Yes No <input type="checkbox"/> <input type="checkbox"/>				
c)	Seated blood pressure measurements	Yes No <input type="checkbox"/> <input type="checkbox"/>		Yes No <input type="checkbox"/> <input type="checkbox"/>		
d)	Questionnaire	Yes No <input type="checkbox"/> <input type="checkbox"/>				
Permission for samples collection and blood tests			Cross box	Initial		
I agree to provide the following samples (individually consented below). The purposes and possible risks of donating these samples have been explained to me. I agree that donated samples will be considered a gift but I will have the right to withdraw permission for analysis.			Yes No <input type="checkbox"/> <input type="checkbox"/>			
I understand that my samples, including the main stocks of any genetic material collected such as DNA and RNA, will be stored in Bristol. I agree that any of my samples (with an anonymous number only), or any information obtained from them including the sequence of my genetic material, may be sent to specialist research laboratories in the UK and abroad for analyses and the results returned to Children of the 90s. Researchers at these laboratories have no access to personal information about study participants.			Yes No <input type="checkbox"/> <input type="checkbox"/>			
Individual samples and blood tests (cross box and initial to give consent)			Consent to test		Consent to inform	
			Cross box	Initial	Cross box	Initial
Individual samples						
a)	Skin swab sample	Yes No <input type="checkbox"/> <input type="checkbox"/>				

b)	1 st Skin biopsy (2mm)	Yes <input type="checkbox"/>	No <input type="checkbox"/>		
	2 nd Skin biopsy (2mm)	Yes <input type="checkbox"/>	No <input type="checkbox"/>		
c)	Blood sample	Yes <input type="checkbox"/>	No <input type="checkbox"/>		

The University of Bristol holds legal liability insurance in the event that any participant is injured due to negligence on the part of the University

Individual sample tests														
d)	Full blood count*										Yes	No	Yes	No
											<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Future use											<input type="checkbox"/>	<input type="checkbox"/>		
e)	I agree to my samples being stored after completion of the visit for use in future genetic studies.										Yes	No		
											<input type="checkbox"/>	<input type="checkbox"/>		
f)	I agree to my samples being stored after completion of the visit for use in future non-genetic studies.										Yes	No		
											<input type="checkbox"/>	<input type="checkbox"/>		
Participant signature														
Initial		Last name												
Date signed			D	D	M	M	Y	Y	Y	Y				
Fieldworker signature														
Initial		Last name												
Date signed			D	D	M	M	Y	Y	Y	Y				

The University of Bristol holds legal liability insurance in the event that any participant is injured due to negligence on the part of the University



UK CIC - Characterisation of COVID-19

long-term immunity – Participant information

We would like to invite you to take part in a new research study. We want to understand more about the immune response to COVID-19. An immune response is the reaction of our bodies to something it does not recognise. In this case the virus that causes COVID-19.

What is the purpose of the research?

In March 2019 a new coronavirus (SARS-CoV-2) was identified that causes the disease COVID-19. This has caused a global pandemic, with millions of people infected. Many scientists are now working to develop vaccines and treatments to help slow the spread of the virus. A number of vaccines are now in use across the UK and the world. However, scientists still do not fully know what level of immune response provides protection against the virus, how long immunity persists following vaccination or the effectiveness of the vaccines against new variants of the virus

Reducing the infection rate and finding effective vaccines and treatments all require a better understanding of how the immune system responds to a COVID-19 infection and vaccination. This study aims to look in detail at the long-term immune response of people who have been infected and compare this to the symptoms they had during the infection. It will also compare long-term health outcomes in people who have and have not had COVID-19.

Why have I been invited to take part?

You have been invited to take part because you are a participant in Children of the 90s and we know whether or not you are likely to have been infected by the virus. We have this information from:

- an answer you gave in earlier questionnaires about COVID-19 OR
- the result of a blood test you completed at home (serology test) for Children of the 90s OR
- information in your NHS medical records indicates you had COVID-19 (if you gave consent for us to look at this)

We are looking for participants in both groups; those who have had the infection and those who have not, so we are able to compare results.

What will I have to do?

We would like you to attend up to 3 visits over a 12-month period.

Visit 1

A 65-minute session at our centre in Oakfield House, where you will;

1. **Provide a blood sample (5 tubes)**
We will ask for a sample of blood from your arm, this will be taken in the usual way. You can eat and drink as normal before providing this sample. Although we will need to collect 4 blood tubes from you this will not be more than 50ml of blood which is about a quarter of a teacup.
2. **Provide a urine and saliva sample.**
3. **Complete the following physical measures:**
Height and weight – We will measure your height and weight so that we can work out your current BMI (Body Mass Index)

Respiratory function test – We will ask you to complete a simple sit to stand test to assess how well you breathe during exercise. We will ask you to get up from a chair and then sit back down as many times as you can in one minute. During this test you will wear a monitor to measure your oxygen level and heart rate.

If you cannot complete a sit to stand test, then you will be asked to complete a 6-minute walk test instead.

4. **Computer based questionnaire.**

You will be asked to complete a short computer-based questionnaire about your quality of life and how you feel when you are doing different types of exercise.

Visits 2 and 3

After the first visit your blood and saliva samples will be tested for the SARS-CoV 2 virus and the number of antibodies to the virus will be measured. The results of this will be used to choose some people to continue with the study.

If you are chosen, we will invite you back to do the same tests 2 more times, 3 months and 8-12 months after your first visit.

If after your first visit you go on to have a positive test for COVID-19 or you have symptoms of COVID-19, please let us know.

If we do not invite you back for further visits, this does not mean you have or have not had COVID-19. It just means the level of the response you have at this time is not suitable for this research study and we will let you know that you do not need to do any more visits.

Because we don't yet know if people can be reinfected, how long vaccinations provide immunity or when people who have COVID-19 are no longer infectious you should continue to follow all government guidance on social distancing to help prevent the transmission of the virus to others.

What will you do with my samples?

- All samples will be stored with unique ID numbers so that we can link your test results to other data about you. Researchers cannot identify you from your samples.
- We will test your saliva for the virus. We will look for the presence of virus RNA (its genetic material) to do this.
- We will look in your saliva and blood to see if we can detect antibodies to the virus, if found, they show that you have been infected by the virus at some point and that your body has responded to this infection. After this, we can then look to see how this response changes at each visit.
- We would like to store some of your blood, saliva and urine for answering more detailed questions. For example, we will store some of your white blood cells, that we know are involved in the immune response. By looking in detail at these cells we will be able to describe how your body has responded to the infection and which parts of the immune system have been involved in this response.

Will you use my blood sample for DNA and genetics?

Some of the tests will involve looking at your DNA. With your consent we will extract DNA from your blood for genetic and epigenetic research. We will also use your samples for RNA analysis. RNA is the genetic material that carries out the instructions of DNA. You can find more information about DNA and genes [here](#).

You can choose separately whether to consent for genetic research without it affecting your involvement in the rest of this research study.

Future research

Most of the research using your samples will take place in Bristol but some of your samples may be made available to researchers working in universities, hospitals or other organisations in the UK or abroad to answer other research questions. We may ask for a 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 will not sell or make any profit from the samples you donate, and they will only be used in ethically approved research.

Your data will be used for research purposes only and will only be analysed by researchers who have been approved by the Children of the 90s Executive. None of these researchers will have access to your personal information.

How your health data will be used in this research

If you have previously consented for Children of the 90s to link to your health data then we will be able to access information like if you have sought advice from your GP or 111 or have had a test completed by the NHS for COVID-19. If you had severe COVID-19 symptoms we will also be able to see if you have had care at a hospital. Understanding details about your care will help the researchers understand how COVID-19 has affected different people.

Am I eligible to take part?

Please note that due to the nature of this study if you do not want to provide a blood sample you will not be able to take part.

You will be unable to take part if you:

- are currently taking blood thinners (e.g. warfarin) or have a known clotting disorder

We may have to delay or stop you taking part if you:

- are required to self-isolate under the latest government guidelines:
 - You or someone in your household/bubble are swabbed positive for Coronavirus or are symptomatic of COVID-19 (new continuous cough, fever or change to or loss of sense of smell)
 - You have been asked to self-isolate by the contact test & trace program
 - You have recently returned from a country on the Government's high-risk list
- are in a 'high risk' category and required to 'shield' during this coronavirus pandemic, or you feel you are high risk of becoming unwell if you were to catch coronavirus (e.g. due to underlying health conditions etc)

Please contact us immediately if you think this may apply to you so we can discuss this with you.

Do I have to take part?

No – it is up to you to decide whether or not to take part. If you decide to take part, you can withdraw from the research at any time by contacting us at Children of the 90s using the contact details enclosed. If you decide not to take part, it will not affect any other Children of the 90s activities that you or your family may be involved in.

Is this COVID-19 safe?

Children of the 90s and the University of Bristol have implemented a wide range of measures to protect staff, students and visitors while they are in and around the University. This includes the use of face coverings, one-way systems and provision of hand sanitiser and hand washing facilities. In addition, staff and participants involved with this study will have a temperature check on arrival at Oakfield House and there will be limited numbers of participants and staff in the building to enable social distancing. Additional PPE will be worn by staff and participants for the blood sample to be taken as this is the only time we will not be able to maintain 2m social distance.

This study is open to participants across the UK, providing you are able to travel in accordance with current UK government guidance. We understand that this is constantly changing, and we will be happy to discuss how we can best support you taking part in this research.

Where will it take place?

Children of the 90s, University of Bristol, Oakfield House, 15-23 Oakfield Grove, Bristol, BS8 2BN

How long will it take?

Each visit should last about 65 minutes. Appointments will be available across the day, including some weekend and evening options.

Will I receive anything for my time?

As a thank you we will offer you £10, in electronic shopping vouchers (or paid by bank transfer on request), for each visit you complete. We will also reimburse your travel expenses and can provide a taxi or free parking at Children of the 90s, if required.

Are there any benefits to me if I take part?

There are no direct health benefits to you for taking part, and this is not a health check or a diagnostic test for COVID-19. We are asking you to help us with research that could help with future treatment and vaccine development for COVID-19.

Are there any risks or disadvantages if I take part?

There are no serious risks involved in taking part. You might find giving a blood sample slightly uncomfortable and you might have a temporary bruise on your arm.

What do I have to do now?

If you want to take part, call us or reply to this email now to let us know your decision and to book an appointment. If you do not want to take part, please let us know so we do not send you any more reminders about this study. You can find our contact details at the end of this information sheet.

Confidentiality and data protection

Any data we collect from you will be stored with an individual ID number but with no personal information (your name, address, or date of birth) attached. Files that link this ID number to your personal details will be securely stored. Data will be used for research purposes only and will only be analysed by researchers who have been approved by the Children of the 90s Executive. None of these researchers will have access to your personal information. Your personal details will not be shared with third parties except for certain service providers working on our behalf. For example, VCars if you ask us to book a taxi for your visit.

Children of the 90s is compliant with GDPR (General Data Protection Regulation) and with the Data Protection Act (2018) for the collection, processing, storage and disclosure of personal information. If you would like to find out more, please see our privacy notice here:

<http://www.bristol.ac.uk/alspac/participants/privacy/>

The results of the study will be published in scientific journals and participants can see a summary of the results. No individual information or names will be published.

What if something goes wrong? What if I have questions or concerns?

If you have questions or concerns about any area of this research, please contact Children of the 90s (telephone 0117 331 0010, or email info@childrenofthe90s.ac.uk). If we are unable to answer your question or concern directly, we will refer this to the Children of the 90s Chief Operating Officer, or you can do this yourself,

Ms Lynn Molloy
Chief Operating Officer
Oakfield House

Oakfield Grove
Bristol
BS8 2BN
Lynn.molloy@bristol.ac.uk
0117 33 10075

Who is organising and funding the research?

This research is organised by Children of the 90s, the principle investigator is Professor Nicholas Timpson. This study is part of the a larger study called 'A UK underpinning platform to study immunology and immunopathology of COVID-19:The UK Coronavirus Immunology Consortium' (or UK CIC), and the PI is Professor Paul Moss who is based at the University of Birmingham. The research is funded by The Medical Research Council

Who has reviewed this research?

- Children of the 90s Executive
- Children of the 90s Ethics and Law Committee (ALEC)
- Children of the 90s Original Cohort Advisory Panel (OCAP)
- An NHS Research Ethics Committee.

Contact for further information

Tel: 0117 331 0011 Email visits@childrenofthe90s.ac.uk

**Thank you for taking the time to read about our COVID-19 research
and for your ongoing support of Children of the 90s.**



UK CIC – Characterisation of COVID-19 long-term immunity consent form

We would like to ask you to take part in all of the following measurements or procedures. Please cross the “Yes” box and initial to indicate that you give consent. Please cross the “No” box and initial if you do not consent.

General consents		Cross box	Initial
I confirm that I have read and understood the information sheet UK CIC – Understanding COVID-19 long term immunity [Information sheet v2.1 08/03/2021.] I have had the opportunity to consider the information and ask questions and I have had these answered satisfactorily.		Yes No <input type="checkbox"/> <input type="checkbox"/>	
I understand that my participation is voluntary and I am free to withdraw at any time without giving any reason, without my legal rights being affected.		Yes No <input type="checkbox"/> <input type="checkbox"/>	
I agree to participate in this study		Yes No <input type="checkbox"/> <input type="checkbox"/>	
I agree to my data being stored after completion of the study for use in other studies		Yes No <input type="checkbox"/> <input type="checkbox"/>	
Consent for individual assessments (cross box and initial to give consent)		Consent to test	
		Cross	Initial
a)	Height	Yes No <input type="checkbox"/> <input type="checkbox"/>	
b)	Weight	Yes No <input type="checkbox"/> <input type="checkbox"/>	
c)	Sit to stand test with oxygen level and heart rate sensor	Yes No <input type="checkbox"/> <input type="checkbox"/>	
d)	6-minute walk test with oxygen level and heart rate sensor (if cannot do STS test)	Yes No <input type="checkbox"/> <input type="checkbox"/>	
Permission for samples collection and blood tests		Cross box	Initial
I agree to provide the following samples (individually consented below). The purposes and possible risks of donating these samples have been explained to me. I agree that donated samples will be considered a gift, but I will have the right to withdraw permission for analysis.		Yes No <input type="checkbox"/> <input type="checkbox"/>	
I understand that my samples, including urine, saliva, blood and blood components (including serum, DNA, RNA and any cells found in the blood sample) will be stored in Bristol. I agree that any of my samples (with an anonymous number only), or any information obtained from them both genetic & non genetic may be sent to specialist research laboratories in the UK and abroad for analyses and the results returned to Children of the 90s. Researchers at these laboratories have no access to personal information about study participants.		Yes No <input type="checkbox"/> <input type="checkbox"/>	
Individual samples and blood tests (cross box and initial to give consent)		Consent to test	
		Cross box	Initial
Individual samples			
a)	Venous blood sample	Yes No <input type="checkbox"/> <input type="checkbox"/>	

b)	Saliva sample	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
c)	Urine sample	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
Future use				
e)	I agree to my samples being stored after completion of the visit for use in future genetic studies.	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
f)	I agree to my samples being stored after completion of the visit for use in future non-genetic studies.	Yes <input type="checkbox"/>	No <input type="checkbox"/>	
Participant signature				
Initial		Last name		
Date signed		D	D	M M Y Y Y Y
Fieldworker signature				
Initial		Last name		
Date signed		D	D	M M Y Y Y Y