



# 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

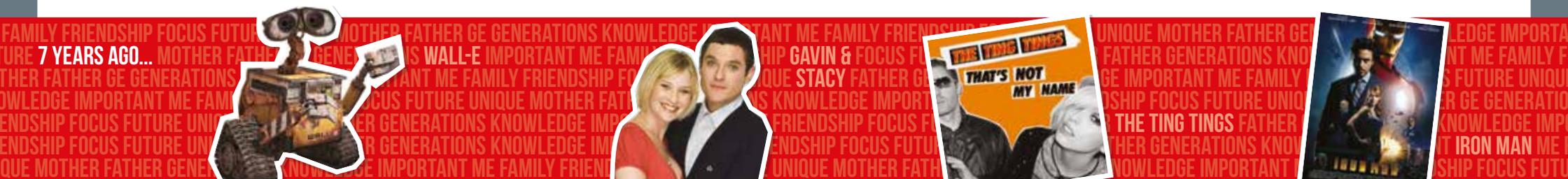
We couldn't have done any of this without you and that's why we'd like you to take part in Focus@24+. The more information we have about you, the better picture we can build up of the health of your generation.

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](http://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

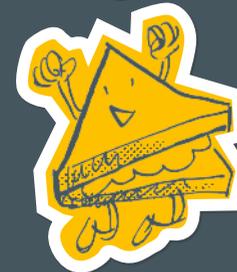


- Arrive at the Children of the 90s Focus Centre for your visit. It will last just over six hours



- 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.

# CONTENTS PAGE

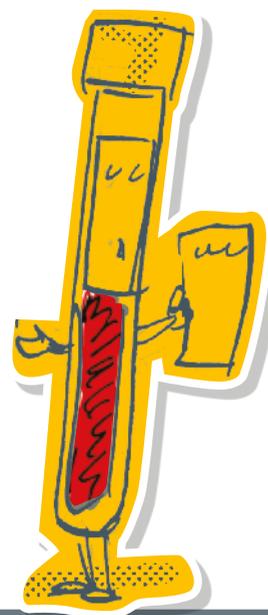
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## SO WHAT'S INVOLVED?

### 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](http://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.

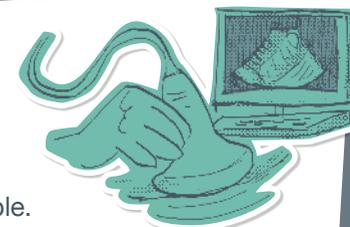
### IS IT SAFE?

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?

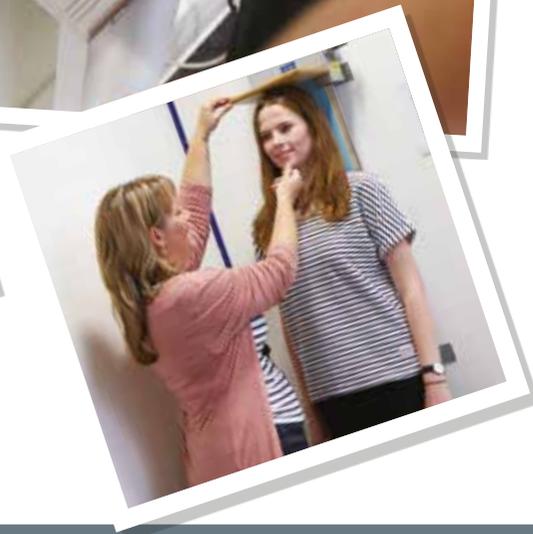
There are no risks involved, although the blood-pressure cuff around your upper arm might feel a little tight and uncomfortable for a moment.





## 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?

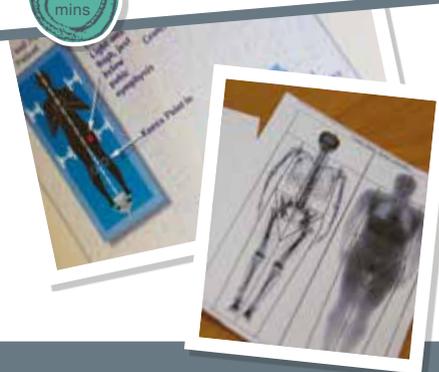
A DEXA scanner is a large scanning machine that measures the amount of calcium and other minerals in your bones. The result is called the 'bone mineral density'. Denser bones have more calcium and minerals. They are stronger and less likely to break.

### 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?

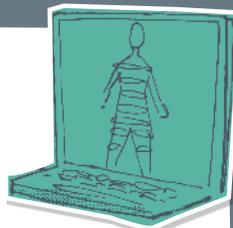
We do this to gather extra information about your size, shape and posture. We do it using a three-dimensional (3D) machine that uses light scanners and computer software.

## 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](mailto:info@childrenofthe90s.ac.uk)
- Web: [www.childrenofthe90s.ac.uk](http://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](mailto:info@childrenofthe90s.ac.uk)

Website: [childrenofthe90s.ac.uk](http://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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**HAVE ANY OF YOUR DETAILS CHANGED?  
NEED MORE INFORMATION?**

**Please get in touch!**



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V3 February 2016