



# Children of the 90s

## Participant information about child visit

We are inviting your child to take part in a Children of the 90s data collection visit.

- Before you book an appointment for your child's visit, it is important for you to understand what the study is, why the research is being done and what it will involve.
- Please take time to read the following information carefully and feel free to discuss this with your family if you wish.
- You are free to decide whether or not you want your child to take part in a visit. If you choose not to take part, this will not affect the involvement of other members of your family or your future involvement with Children of the 90s.
- We always welcome back anyone who hasn't been part of the study for a while.
- If you require this information in an alternative format e.g., large print, then please contact us.
- Ask us if there is anything that is not clear of if you would like more information.

We are excited to welcome you and your child to our next Children of the 90s clinic.

The data you and your family have given throughout the last 30 years helps scientists around the globe learn so much about what helps make us into healthy, happy individuals. Understanding the risks or reasons behind why some people develop serious illness such as cancer, diabetes, dementia and other don't, is made possible using longitudinal data from studies such as ours. This has been shown recently in how we have been able to respond to the global COVID-19 pandemic and provide vital information to researchers and policy makers in a way that no one else could.

The scientific potential is exciting as we continue to follow you and your families through childhood and adulthood and into older age. Ours is the only global study with such detailed participant data over three generations – this means that each of you is unique and special.

The overall aim of the study is to collect detailed data on the health and wellbeing of all the original Children of the 90s participants, this now includes following their children (known as COCO90s – Children of the Children of the 90s).

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### Recent Children of the 90s news

- We welcomed our 1,500th child of the Children of the 90s.
- We published our 2000th research paper.
- In 2018 we were recognised as Biobank of the year.
- We have been funded by the Medical Research Council, Wellcome Trust and University of Bristol.
- We have been able to contribute significantly to research about the COVID-19 pandemic for example: Due to COVID-19, [emotional and behavioural problems similar to those experienced during the "terrible twos" were seen in older primary school aged children](#) - raising concerns about the long term impact of the pandemic on young children's mental health.

## Why has my child been invited to take part?

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Your child has been invited to this study because you are a participant of Children of the 90's and you have enrolled them into Children of the 90s either as part of our COCO90s study or you have completed an enrol your family form.

Children of the 90s is interested in how becoming a parent and how your children's health and wellbeing impacts on you. Children of the 90s is what's known as a longitudinal study – research that follows the same group of people over time. That makes you and your family irreplaceable.

Your child may have attended visits with us before and they have now reached the age for their next visit or this could be their first visit. All your children are important to us, and to the teams who use your data every day in their research.

## What do I need to do if I want my child to take part?

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All you need to do is book an appointment:

- By using our online booking system, your unique link is in your invite letter.
- By emailing us on [visits@childrenofthe90s.ac.uk](mailto:visits@childrenofthe90s.ac.uk) with best contact number and time and we will call you to book your appointment.
- You can call us on 0117 331 0011 and we will book your appointment for you.

## What will it involve if they take part?

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Your child will be invited to attend a series of visits, each visit takes about 1½ hours. You can choose whether or not you want them to take part in each visit without it affecting their future involvement. What happens at each visit is given in more detail below.

## Where will their visit take place?

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The visit will be at our Clinic at Learning and Research Building, Southmead Hospital BS10 5NB.

If you are unable to travel to Bristol, then we can arrange a shorter 'virtual visit' that includes some but not all of the measures.

### *Important facts about your visit*

- All our visits take place at our centre in Bristol.
- If you can't travel to Bristol, we can now offer a "virtual visit" alternative.
- We pay **all** your travel expenses.
- We can book and pay for a taxi for you.
- We can book and pay for overnight accommodation for you.
- We pay your parking fee.
- We will give your child a gift or, for older children a, £10 gift voucher to thank them for taking part.
- We can give you a letter for your child's school to request an authorised absence (and one for your employer too).
- We have appointments available throughout the day, evenings and weekends and school holidays.
- All our child visits take about 1½ hours.

## What will happen to their information?

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Any data and samples we collect from your child will be stored with an individual ID number, no personal information (name, address or date of birth) will be attached. Files that link this ID number to their personal details will be securely stored and kept strictly confidential and separate from their personal information. The data and samples 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 their personal information. 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.

You can see our privacy policy for more information:

[Privacy | Avon Longitudinal Study of Parents and Children | University of Bristol](#)

We may share your details in exceptional circumstances, where we feel there is a risk to the safety of your child or someone related to them, but we would always discuss this with you first.

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.

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.

## Do they have to take part?

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Your child's participation in this study is completely voluntary and is an addition to **your** own involvement in Children of the 90s. If you do decide that you do not want your child to take part, this will not affect **your** continued participation in Children of the 90s.

We understand the commitment involved in taking part in research and that having young children is a very busy time in your life, so we will always give you the option not to come to an individual visit, give a sample or complete a questionnaire if it is not convenient for you. This will not affect you being invited in the future. Also, you are free to withdraw at any time without giving a reason.

## How is the study managed and funded?

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This research is organised by the Children of the 90s study team. The Scientific Directors are Professor Nic Timpson and Professor Deborah Lawlor. The study has been funded by the Medical Research Council, the Wellcome Trust, the University of Bristol, the local Clinical Research Network (CRN) and the John Templeton Foundation. The scientific value of the study was reviewed by anonymous reviewers and grant board members for the MRC, Wellcome Trust and John Templeton Foundation, and the ALSPAC Executive.

The original cohort advisory panel (OCAP) made up of study participants were involved during the design and planning phase of the study.

ALEC (The Children of the 90s Law and Ethics Committee) made up of experts in research ethics and study participants, have approved the overall aims of the study.

### ***How to contact us***

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

Tel: 0117 331 0011

Email:

[visits@childrenofthe90s.ac.uk](mailto:visits@childrenofthe90s.ac.uk)

Website:

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

### ***Who do I contact if there is a problem?***

You can contact us at any time using the details at the end of this document and our team will be happy to answer any questions you may have.

If you want to make a complaint, please contact our Chief Operating Officer:

Ms Lynn Molloy  
Children of the 90s  
Learning and Research Building,  
Southmead Hospital  
Bristol  
BS10 5NB.

[Lynn.molloy@bristol.ac.uk](mailto:Lynn.molloy@bristol.ac.uk)

0117 3310075

The NHS research ethics committee (London - Queen Square Research Ethics Committee), an independent group that looks at all research involving NHS patients and who are there to protect your safety, rights, well-being and dignity, have approved this study.

## What are the advantages and disadvantages of taking part?

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The clinic is not a health check and we are asking your child to help us with research that we hope will help people in the future. Some of the measurements that we take might indicate increased risk for some health problems. Where you have given us written consent for us to feedback any results for these tests, we will advise you about their result and give you a letter to take to their GP. Other measurements taken are useful for research, but their results have no clear medical meaning therefore, we will not tell you about those results.

We do not see any major disadvantages in taking part.

## Will you tell our GP (General practitioner/family doctor) about their involvement in the study?

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We will not inform your GP that they are a participant in the study or what tests they have done. If their blood test results or blood pressure are out of the normal range and you have given us consent, we will give you a letter you can give to their GP.

## Transmissible infection safety precautions

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- You are welcome to wear a mask if you prefer
- Most of our systems are now electronic, for example we will not issue paper vouchers or cash. These will be electronic or by bank transfer.
- We will not have the large café offering a full selection of food a drink as before. We will have a space where you can sit and have a drink and small snack.
- All clinic rooms will be cleaned between each participant.
- You have any concerns about visiting. We are able to offer some of the visit measures in a 'virtual visit' option.

Our safety measures are regularly reviewed.

# What will happen at the visit?

We will invite your child to a number of visits from 6 months after they are born up until they are a teenager. The measures they complete at each visit depends on how old they are. We have given details of all the measurements that the children could be asked to do and explained at what age they will do them. Remember they will not be asked to do all of these at any one visit.

## Consent

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At the start of each visit we will go through all the tests for the day with you and answer any questions you may have. We will ask you to complete and sign a consent form for each individual test. They only have to do the parts that you are happy with.

We will also ask you some general questions about their health and lifestyle that help us understand the data we get from the other measurements. Things like:

- Current medications and allergies.
- Any fractures they may have had.
- When they started crawling, standing and walking.
- And, for older girls, whether or not they have started their periods.

During the consent session we will ask your permission to link your child's data to their official health, education and environmental records, this is a process called data linkage.

We will ask if you are happy, or not, for Children of the 90s to use your child's 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.

The tests that will be carried out at each visit will be different depending on how old your child is. Information about all the possible tests is given in this information sheet but please remember they will not be asked to do all the measures in one go. All the information we collect can be linked together to provide a detailed picture of your child and this will help answer important health and social research questions.

## Physical measures

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### BODY MEASUREMENTS (ANTHROPOMETRY) – EVERY VISIT

We will measure the following:

1. Height or length
2. Weight
3. Circumferences: waist, head, arm and hip
4. Skinfolds - This is a technique that estimates how much fat is on the body. It involves a trained fieldworker using a device called a calliper to lightly pinch the skin and underlying fat in several places including the tummy, arm and leg.

### BLOOD PRESSURE – EVERY VISIT FROM 6 MONTHS OLD

This is done in the same way as for an adult using special child sized cuffs. We will explain the process to your child and demonstrate how the cuff will inflate and deflate. We will try to take two readings if your child remains happy for us to do so. If your child's blood pressure is higher than expected for their age, we will give you a letter to take to your GP. They will probably want to repeat this test.

#### ***Does my child have to do all the measures?***

- No
- You will be given the option to agree or not agree to each measure.
- You do not have to give a reason for your choice.
- It will not affect your or your child's ability to continue with the study if you choose not to do certain measures or even a whole visit.
- You are free to withdraw your child from the study at any time.
- If your child is 9 years or older, we will also ask for their assent.

## GRIP STRENGTH – FROM 9 YEARS OLD

We would like to measure their grip strength. This is a simple test that involves squeezing a small measuring device called a spring dynamometer. This indicates their general muscle strength and condition.

## ECZEMA ASSESSMENT – EVERY VISIT FROM 6 MONTHS OLD

We would like to look at your child's skin in certain areas of their body, for example the back of their neck, arms and legs, to see if there are any signs of eczema. If there are, we'll look to see how much of the area the eczema covers. We will also ask you a few questions about how bad their eczema has been in the last week.

## ASSESSMENT OF YOUR CHILD'S THINKING, UNDERSTANDING AND MOVEMENT – EVERY VISIT

At each visit we will ask you if your child is able to complete certain activities, for example when they are very young, we will ask you if they have started to smile or make certain sounds. As they get older, we will ask you if they have started to brush their own teeth or make their own breakfast.

We will also ask them to complete little task like jumping, building a tower with blocks or drawing a picture.

When they are 4 years old, we will also ask them to complete 3 short (about 5 minutes each) iPad-based games to assess their memory, reasoning, flexibility, and problem-solving skills. These games test if your child can control their thoughts and behaviours to catch fish, sort cards, and memorise the position of coloured dots.

## DXA WHOLE BODY SCAN – FROM 7 YEARS OLD

A DXA 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.

A member of staff will ask your child to lie on a scanner and stay very still. The machine's arm will pass over their whole body.

### ***Is a DXA scan safe?***

- Yes, although we will ask you not to accompany your child during the scan, this is especially important if you are also having a scan, or you are (or could be) pregnant.
- DXA scans use a much lower level of radiation than X-rays.
- DXA scans use less radiation than the amount we are exposed to in our daily lives.

### ***Important information about your visit***

- *Your child should wear loose comfortable clothing that is easy to take off and put on.*
- *Try to avoid clothing with metal fastenings or zips.*
- *A note of any regular medications they take.*
- *Remember to bring your child's health record (red book).*
- *Bring any favourite toys, iPads etc.*
- *For younger children remember to bring nappies, food or anything else you may need.*

## Biological samples

Children of the 90s collects biological samples as they can give us lots of information about the health of our study participants and about their environment. The use of biological samples is carefully regulated:

- The Human Tissue Authority (HTA) is a public body of the Department of Health and Social Care in the United Kingdom.
- It regulates the removal, storage, use and disposal of human bodies, organs and tissue for purposes such as research, transplantation, and education and training.
- The Human Tissue Authority provides guidelines (a code of practice) to researchers on what we are and are not allowed to do.
- Children of the 90s has ethical approval to collect samples and we abide by the HTA code of practice.
- The building where the samples are stored and managed also has a licence from the Human Tissue Authority.

We will ask your child to provide the following biological samples:

### BLOOD SAMPLE – 6 YEARS OLD AND THEN 9 YEARS ONWARDS

When your child is 6 years old, we will ask your consent to take a blood sample from them. If your child is older than 9 years of age, we will also obtain their assent to make sure they are happy to provide this sample.

If you consent to a blood sample, local anaesthetic cream will be used on their arm which will stop your child feeling any discomfort.

Blood samples will be measured immediately for their haemoglobin level, this is a test that can tell if your child is anaemic. If the result is lower than expected for their age, we will give you a letter to take to your GP who will probably want to repeat the test,

### SALIVA SAMPLE

If you/they do not wish to provide a blood sample, or we are unable to take a sample, we will ask them to provide a saliva sample instead. This sample can also be used to obtain DNA but cannot be used for non-genetic studies.

### URINE SAMPLE – FROM 9 YEARS OLD

The kidneys filter blood, remove substances the body does not need and excretes them in the urine. Therefore, urine can tell us about things that your child may have been exposed to. It can also give a measure of their body's responses to its environment. For instance, it can show how their body reacts to things like viruses, pollen or certain foods. We will ask them to provide a urine sample during their visit.

### WHAT WILL HAPPEN TO THEIR SAMPLES?

After the initial test detailed above and with your consent, we would like to store the remainder of their samples so we can use them for answering future research questions that arise, for example, to look at changing hormone levels as they get older. The samples are stored with unique ID numbers allowing test results to be linked to other data, but researchers using the samples will not be able to link these results to any personal information such as their name, age or date of birth.

### ***Is there risk for my child giving a blood sample?***

- At any time during the sample taking you can ask for the procedure to stop.
- If your child refuses or becomes upset at any stage, we will stop.
- There may be some bruising, though our staff aim to minimise this.
- Some people faint when having a blood sample taken, this could happen even if it has never happened before.
- We only take blood samples with your child lying on a couch to reduce the risk of injury should they faint.
- If they do faint, we will make sure they are fully recovered before discussing if they wish to continue.

Most of the research using the samples will take place in Bristol. Some samples may also be made available to researchers working in other universities, hospitals or other organisations in other parts of the UK or abroad. The samples that you donate will not be sold for profit and will only be used in ethically approved research in the field of biomedical research. We may ask for a fee from researchers to help cover the costs of running the biobank where the samples are stored.

Another reason we take samples is so we can have a sample of your child's DNA, the study of DNA and genes is referred to as genetic research. Our genes play an important role in defining many characteristics about individuals and some can make us more or less likely to develop many common diseases. We all have a slightly different set of genes in our bodies. Genetic studies can help us look at these differences and understand varying characteristics and the causes of diseases. You can choose not to consent for genetic studies but still provide samples for non-genetic research.

## Questionnaires

### ABOUT YOUR CHILD

We will send you a link to complete an online questionnaire about your child before each of their visits. You can complete this even if you don't want them to attend the visit.

## Feedback of results

If we do not feedback any results to you, you should not conclude this means your child has a clean bill of health. If they have any symptoms that cause you concern you should contact your GP in the way that you normally would.

The following describes which of the test results we plan to provide feedback on (if you have given us consent to do so):

- If their **blood pressure** is high, we will tell you at the clinic and give you a letter to take to your GP.
- If they have low haemoglobin (risk of **anaemia**)

In all cases we will give you a letter to take to your GP so that they can repeat the test, discuss this with you, and do further tests if necessary. This is because lots of things, apart from anaemia, can cause low haemoglobin including if they are feeling unwell or recovering from an illness.

## Support services

If you or your child are suffering from mental health problems, please seek advice from your GP or look at the links below.

### *Specialist Mental Health Services*

Avon and Wiltshire Mental Health Partnership: <http://www.awp.nhs.uk>

### *Children's Centres*

<https://www.bristol.gov.uk/schools-learning-early-years/childrens-centre>

### *Charities*

Bluebell: <http://www.bluebellcare.org>

Mothers for Mothers: <https://www.mothersformothers.co.uk/>

The Maternal Mental Health Alliance: <http://maternalmentalhealthalliance.org>

[More information about genetic studies and how we use biological samples can be found here ;  
\[https://www.bristol.ac.uk/media-library/sites/alspac/documents/participants/PIS\\\_DNA.pdf\]\(https://www.bristol.ac.uk/media-library/sites/alspac/documents/participants/PIS\_DNA.pdf\)](https://www.bristol.ac.uk/media-library/sites/alspac/documents/participants/PIS_DNA.pdf)

### ***When and how will I receive any feedback?***

- You will receive their blood pressure results immediately.
- If they have blood values outside the normal range and you have given consent for feedback, you will receive a letter up to 4 weeks after your visit.

**Thank you for your time in reading and for your ongoing support of Children of the 90's.**