



CHILDREN OF THE CHILDREN OF THE 90s STUDY (COCO90s) PARTICIPANT INFORMATION

WE ARE INVITING YOU AND YOUR FAMILY TO JOIN CHILDREN OF THE CHILDREN OF THE 90s (COCO90s).

We know that you already participate in the Children of the 90s (CO90s) study - thank you! We are now inviting you, your partner and your pregnancies/children to join the Children of the Children of the 90s (COCO90s) part of the Study.

- Before you join the Children of the Children of the 90s study (COCO90s), 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 to join the study. If you choose not to take part, this will not affect the involvement of other members of your family, nor will it affect your participation in Children of the 90s.
- Please ask us if there is anything that is not clear or if you would like more information.

1. WHAT IS A LONGITUDINAL STUDY?

A longitudinal study is a type of research project that involves collecting information from the same people over an extended period of time. The Children of the 90s are a group of around 14,500 children born in or near Bristol between 1991 and 1992. Scientists have been studying them ever since and are constantly making discoveries that make a difference to lives around the world. CO90s has been running for over 30 years and we have received funding to keep following-up all our participants, including their new families (partners and children). This part of the Study involves Children of the 90s who are pregnant or already parents, their partners and their children, and is called "Children of the Children of the 90s (COCO90s)".

2. WHY AM I BEING INVITED TO TAKE PART?

We are very excited that many of the Children of the 90s have children of their own, and we are keen to follow these pregnancies, births, babies and children. It will mean Children of the 90s will have unique data from three generations of families, so that scientists can research key social and health issues.

It doesn't matter how much your family has been involved in the past, we would love you to be involved in this ground-breaking research.

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How to contact us

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

Tel: 0117 331 0011

Email: info@childrenofthe90s.ac.uk

Website: www.childrenofthe90s.ac.uk

Or join us on [Facebook.com/childrenofthe90s](https://www.facebook.com/childrenofthe90s)

You are receiving this invite because:

- You are one of our original participants and you have told us that you have a child or pregnancy you want to include in the study.

Or

- You are the partner of one of our original study participants.

3. WHAT ARE THE AIMS OF THE CHILDREN OF THE CHILDREN OF THE 90S STUDY?

Since the recruitment of mothers during pregnancy in the early 1990s, thousands of Children of the 90s have attended focus visits to collect data such as height, weight and blood pressure, completed questionnaires and taken part in other research. This information has been used by researchers around the world and some of our key discoveries are shown here. (see right panel)

We want to continue our ground-breaking research which is based upon long term detailed health data given by the Children of the 90s and their parents. Studying the next generation, and partners as well, will help us understand how genes and, lifestyles can affect health and development. As a result of the advances in technology we are able to obtain a lot more information about your biological health from any samples you donate

4. WHAT DO I NEED TO DO TO JOIN CHILDREN OF THE CHILDREN OF THE 90S STUDY?

Children of the 90s participants:

1. You need to complete the enclosed consent form to let us know that you want your pregnancy, or any children you already have, to be enrolled in children of the children of the 90s (COCO90s)
2. Pass this information on to your partner in person or by post in the pre-paid envelope provided
3. We **must** have received your consent form and the details about your pregnancy/child before we can invite your partner to take part.
4. Please return your completed consent form in the enclosed pre-paid envelope

Partners of Children of the 90s participants:

PLEASE COMPLETE AND RETURN THE CONSENT FORM IN THE PRE-PAID ENVELOPE



Key discoveries by children of the 90s

- *Babies sleep more safely on their backs – lead to the ‘Back to Sleep’ campaign, saving thousands of lives.*
 - [Iodine deficiency in pregnancy adversely affects children’s cognitive development.](#) This research led to the production of a [fact sheet for the public](#), including pregnant women, which provides advice on how to ensure adequate iodine intake through the diet (2013).
 - [Babies exposed to skin creams containing peanut oil were more likely to develop a peanut allergy.](#) Now, all products must clearly list the ingredient, and many have removed it (2003).
 - [The proportion of young people experiencing anxiety during the COVID-19 pandemic almost doubled](#) when compared to previous levels, increasing from 13% to 24% (2020)
- National guidance and health services for women have significantly improved after Children of the 90s-based studies revealed how common maternal depression is both during, as well as after, pregnancy.*

5. What will it involve if I join the study?

- The first step is returning your consent form. This gives us permission to add you and your families' details to our COCO90s database and to use these details to invite you to future COCO90s research activities.
- You can take part in as many or as few activities as you want to.
- These activities may include answering questionnaires online, visiting our centre clinic in Bristol with your child/children and partner if applicable where all family members will be assessed. In our centre we measure things like blood pressure, weight, bone scans, developmental assessments and cognitive assessments. We also collect and providing biological samples such as blood, saliva and urine if you are happy for us to do so.

We will also ask for your permission to access information in your official records, and your children's "red book" child health records.

- You will be invited to each activity separately and will be given information at the time that will help you decide if you want to take part. You will always be able to ask questions before making your decision.
- We will keep you updated on our research through regular newsletters and social media posts.

6. WHAT WILL HAPPEN TO MY INFORMATION?

- Any personal data such as contact details from you, your children and partner if applicable, and research data will be stored securely on University of Bristol servers and will only be used to contact you about Children of the 90s and COCO90s research activities. We will not share your data unless it is necessary for our research activities – for example.
- we may share your address if we use a mailing company to send out our invitations, or we will pass your address to the taxi company or hotel company we use if you ask us to make a booking on your behalf. More information can be found in our privacy notice.

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

Any research data and information you consent to give us is stored with a unique ID number. Researchers will never see your name, address or exact date of birth (sometimes researchers will be given the month and year of birth, for example if they wanted to study the effects of when you were born on how you did at school).

The research data information we keep about you is held securely, on University of Bristol password protected computers, and access is restricted to key Children of the 90s staff.

In exceptional circumstances, where we feel there is a risk to the safety of you or a child, we may share your details with relevant services.



7. DO I HAVE TO TAKE PART?

No! Participation in COCO90S is completely voluntary. If you and/ or your partner decide not to take part this will not affect other family members' continued participation in Children of the 90s.

WE UNDERSTAND THE COMMITMENT INVOLVED IN TAKING PART IN RESEARCH, 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. ([HTTP://WWW.BRISTOL.AC.UK/ALSPAC/PARTICIPANTS/OUR-COMMITMENT-TO-YOU/CHANGING-YOUR-MIND/](http://www.bristol.ac.uk/alspac/participants/our-commitment-to-you/changing-your-mind/))

8. HOW IS THIS STUDY MANAGED AND FUNDED?

Children of the 90s and COCO90S90's are run by the University of Bristol. Expert scientists and managers oversee this research. Our Principal Investigator is Professor Nic Timpson.

The study is funded by -Wellcome, the Medical Research Council, the University of Bristol and the Clinical Research Network. We also obtain funding from other sources for specific research activities, and we would always declare this information.

Research we do is approved by the following groups:

- The Children of the 90s Executive, which is made up of senior researchers and managers.
- The NHS research ethics committee (e.g London - Queen Square Research Ethics Committee). This is an independent group that looks at all research involving NHS patients. It is there to protect your safety, rights, well-being and dignity.
- The ALSPAC Public and Participants Advisory Panel which is made up of Children of the 90s participants.
- 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.

9. How to contact us

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 Lynn.molloy@bristol.ac.uk

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