



CHILDREN OF THE CHILDREN OF THE 90s STUDY (COCOs) PARTICIPANT INFORMATION SHEET

CONTENTS

1. Invitation to COCOs	1
2. What is a longitudinal study?	2
3. Why am I being invited to take part?.....	2
4. What are the aims of the Children of the Children of the 90s study?	2
Key discoveries by children of the 90s:	2
5. What do i need to do to join Children of the Children of the 90s study?	3
If you are a Children of the 90s participant:.....	3
If you are a Partner of a Children of the 90s participants:.....	3
6. What will it involve if I join the study?	3
7. What will happen to my information?.....	3
8. Do I have to take part?	4
9. How is this study managed and funded?.....	4
10. How to contact us	4

1. INVITATION TO JOIN COCOS

Thank you for expressing an interest in taking part in the Children of the Children of the 90s (COCOs) study based at the University of Bristol. A focus in the next phase of the Children of the 90s study is following life events like pregnancy, parenthood and caring for children. Therefore, we would like to invite you to register you and your family which includes your partner (if applicable) and your pregnancies/children to join the Children of the Children of the 90s (COCOs) part of the Study.

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.

Before you take part in COCOs, 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. 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.

2. 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). 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 in our COCOs study. 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.

3. WHY AM I BEING INVITED TO TAKE PART?

This next part of the study is called COCOs and follows:

- You, if you are currently pregnant or have parental responsibility for a child/children*
- Your partner if they are currently pregnant or have parental responsibility for your child/children
- Your child/children

**This includes all children for whom you have any kind of parental responsibility - whether legal or informal - based on your role in the child's life. If you consider yourself to have a parenting role or responsibility for the child, you and they are eligible to take part.*

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.

4. 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 below.



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. [Depression in women during pregnancy | Avon Longitudinal Study of Parents and Children | University of Bristol](#)

More of our discoveries can be found here: <https://www.bristol.ac.uk/alspac/participants/discoveries/>

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, will help us understand how your genes and lifestyle 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.

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

IF YOU ARE A CHILDREN OF THE 90S PARTICIPANT:

1. Please click on the link sent to you in the email to complete the registration form and details about a pregnancy and/or child/children.
2. If your partner would also like to join COCOs, please provide us with your partner's email address on your registration form so we can send them their own consent and registration form.
3. We **must** have received your registration form with your partner's email address included and the details about a pregnancy/child before we can invite your partner to take part.

IF YOU ARE A PARTNER OF A CHILDREN OF THE 90S PARTICIPANTS:

1. Once your partner has provided us with your email address, you will receive an email with a link to a registration form.
2. Please click on the link to complete the form and any details about a pregnancy and/or child/children.

6. WHAT WILL IT INVOLVE IF I JOIN THE STUDY?

- The first step is completing your online registration form. This gives us permission to add you and your family's details to our COCOs database and to use these details to invite you to future COCOs research activities.
- You can take part in as many or as few activities as you want to.
- These activities may include answering questionnaires online and visiting our clinic at Southmead Hospital 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 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.
- As a thank you for taking part, we'll give you a shopping voucher when you attend clinic visits.

7. 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 COCOs 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.



8. DO I HAVE TO TAKE PART?

No. Participation in COCOs is completely voluntary. If you and/ or your partner decide not to take part this will not affect you or 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. 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/>)

9. HOW IS THIS STUDY MANAGED AND FUNDED?

Children of the 90s and COCOs 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 Research Delivery 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 and members of the public.
- 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.

10. 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

If you are still unhappy you can raise your concern or query to the University's Research Governance Team at research-governance@bristol.ac.uk

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

Tel: 0117 331 0011

Email: info@childrenofthe90s.ac.uk

Website: www.childrenofthe90s.ac.uk

Facebook: [Children of the 90s](#)

Instagram: [children_of_the_90s](#)

X: [CO90s](#)

LinkedIn: [Children of the 90s \(ALSPAC\)](#)

Children of the 90s
University of Bristol
Level 1, Learning and Research Building
Southmead Hospital
Bristol
BS10 5NB

