



CHILDREN OF THE 90s STUDY PARTICIPANT INFORMATION

WE ARE INVITING YOU AND YOUR FAMILY TO JOIN A LONGITUDINAL RESEARCH STUDY.

- Before you join the Children of the 90s study, 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.
- Please ask us if there is anything that is not clear or if you would like more information.

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 the Avon area 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. The study has now been running for 30 years and we have received funding to follow-up all our participants again we are going to call this period of data collection @30.

WHY AM I BEING INVITED TO TAKE PART?

The @30 data collection period will involve the collection of data from our original study participants and their parents. We are also very excited that the Children of the 90s are now having 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 study 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:

visits@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 join the study.
- You are the partner of one of our original study participants.
- You are the parent of one of our original study participants who has not enrolled previously.

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

Since recruitment of their mothers during pregnancy, in the early 1990s, and their subsequent births, 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 remote data collections. 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 to be at the forefront of health research and we are in a unique position to be involved in ground-breaking research because we already have detailed information from many of the Children of the 90s and their parents. Studying their children and partners as well will allow us to look at the effect genes, lifestyles have on health and development across three generations.

WHAT DO I NEED TO DO TO JOIN THE STUDY?

Please complete the enclosed consent form and return it to use in the pre-paid envelope.

WHAT WILL IT INVOLVE IF I JOIN THE STUDY?

- The first step is returning your consent form. This gives us permission to add your details to our database and to use these details to invite you to future 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 in Bristol for measurements like blood pressure, weight, vision and hearing, or giving us permission to access information in your official records, for example COVID-19 test results.
- 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.

WHAT WILL HAPPEN TO MY INFORMATION?

Your personal data will be stored securely on University of Bristol servers and will only be used to contact you about Children of the 90s research activities. We will not share your data unless it is necessary for our research activities – for example,

Key discoveries by children of the 90s

- *Babies sleep more safely on their backs – leading to the ‘Back to Sleep’ campaign and saving thousands of lives.*
- [Iodine deficiency in pregnancy adversely affects children’s cognitive development.](#) *This research led to 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).*

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 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 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.

DO I HAVE TO TAKE PART?

No! Participation in Children of the 90s is completely voluntary. If you 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/>)

HOW IS THIS STUDY MANAGED AND FUNDED?

Children of the 90s is run by the University of Bristol. Expert scientists and managers oversee this research. The current Principal Investigator is Professor Nic Timpson.

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

All the 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 (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 Original Cohort 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.

What do I do next?

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 enrolled in children of the 90s.
2. Pass this information onto your partner or parents to see if they wish to enrol.
3. We must have received your consent form and the details about your pregnancy/child before we can invite them to take part.

Partners and parents of Children of the 90s participants:

Complete and return the consent form in the pre-paid envelope.

Who to 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
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