

THE DETAIL



PLAYING A PART
IN THE FUTURE OF



WHO ARE CHILDREN OF THE 90s?

Children of the 90s are a group of nearly twenty thousand young people, born in 1991 and 1992 around Bristol. Scientists have studied these young people ever since.



Discoveries made by these scientists working on Children of the 90s are making a difference to lives around the world.

Am I one of the
Children of the 90s?

Yes! That's why we are writing to you. You may already know that you're part of Children of the 90s. Or perhaps you didn't realise you were part of this special group of people and you've never taken part in the study before. We want to thank those of you who have done so much over the years to help, your efforts have made all our discoveries possible.

But it doesn't matter how much or how little you've done in the past, we want you to play your part in the future of Children of the 90s. In doing so you'll really be making a difference.



Find us on
facebook.
[facebook.com/childrenofthe90s](https://www.facebook.com/childrenofthe90s)

What are you asking me to do?

At the moment, all we're asking you to do is make two decisions and send back a consent form telling us what your decisions are. This booklet contains information to help you make the right decision.

It has two parts:

1

BEING A PART OF CHILDREN OF THE 90s

Pages 4-16 of this booklet explains everything you need to know to help you make the right decision.

We want you to decide if you're happy for us to store your details on our database so that in the future we can contact you – for example to invite you to fill in a questionnaire or come to a clinic. You will always be free to say no to these invitations.

2

MAKING A DIFFERENCE JUST GOT A WHOLE LOT EASIER

Pages 17-30 of this booklet explains how to take part the 'easy' way.

We want you to decide if you're happy for us to collect scientifically important information from your official records, for example your NHS records, to use in our research. We will securely collect this information after identifying your records through a process called 'data linkage'.



WHY ARE YOU WRITING TO ME NOW?

The Children of the 90s are no longer ‘children’. You’re an adult now and if you’re going to take part in the future of Children of the 90s we need to ask for your own consent.

WHY CHILDREN OF THE 90s IS SO IMPORTANT

The aim of Children of the 90s is to help discover the causes of the most important health and social problems facing the world today so that we can prevent those problems.

No other research project of this kind has as much detailed information on as many people on the factors that might shape our lives.

Scientists across the world describe Children of the 90s as the “jewel in the crown” of medical research projects.





HOW YOU PLAY A PART

Over the last 18 years, thousands of members of Children of the 90s have attended clinics. They have filled in questionnaires and provided us with a huge store of information on the things that may influence peoples health and wellbeing across the course of their lives.

Children of the 90s will keep this store of information for researchers to use for as long into the future as is possible, this may be 10s or even 100s of years. This will give researchers the best opportunity to make the most out of the help you have given us.

These clinics and questionnaires will continue in the future, but increasingly we'll look to other ways to collect the information we need.

In particular we want your permission to use the routine information that's collected on all of us by health, social and other services and official organisations.

We hope this will make it easier for members of Children of the 90s to play their part.

More about this in section 2 (from page 17)

SOME PROJECTS WE ARE WORKING ON NOW:

Genetics:

Our genetic research has led to a greater understanding of how genes influence health. This has included studies of genes influencing our blood pressure, height and weight and lung function.

Exercise & Weight loss:

Children of the 90s research has confirmed the importance of exercise to maintaining a healthy weight in children. The research highlighted that short, sharp bursts of vigorous exercise are more effective than longer moderate exercise for losing weight.

"Epigenetics":

Children of the 90s are at the forefront of the new science of "epigenetics". The same genes can have different effects depending on whether they are switched "on" or "off". We are investigating these influences on many aspects of our makeup from IQ to obesity.

Want to know more?

www.bristol.ac.uk/alspac/media/press

What you have helped us discover

The main discoveries of Children of the 90s will be in the future, because most health problems happen in adulthood. Despite this, Children of the 90s have already made many important scientific discoveries about childhood problems. You can look at the full list on our website but here are some examples:

COT-DEATH

The “Back-to-Sleep” campaign arose from research in Bristol and has saved the lives of thousands of babies. More recently Children of the 90s have confirmed the benefits of babies sleeping on their back and also importantly have shown that this has no unintended harmful effects.

PEANUT ALLERGY

Research from Children of the 90s showed that a potentially fatal peanut allergy may be caused by the use of skin creams containing peanut oil in early life. All these creams must now carry a warning label of this possible danger.

OILY FISH IN PREGNANCY

Experts had long been unclear on the advice to give pregnant women on the safety of eating oily fish because of concerns of the level of poisonous mercury it might contain. Children of the 90s research showed that these concerns were unfounded and that mothers who eat oily fish during pregnancy may increase the IQ of their children. Official guidance on diet during pregnancy was changed as a result of this.



COSTS, BENEFITS AND RISKS TO YOU:



Taking part in Children of the 90s will take up some of your time; we don't underestimate the value of this. Taking part in the study won't cost you anything apart from your time. The main benefit is the knowledge you're making a difference.

You provide us with detailed information, some of which is very personal and sensitive. We promise to keep this information confidential, secure and only use it for our research.

Children of the 90s don't feed back any information you have given us or the measurements taken in the focus clinics. A page on our web site explains this in more detail.

What if I change my mind?

Even if you sign up to Children of the 90s now you can change your mind at any time. This could be about one particular bit of the study or being in Children of the 90s in general.

There's more information on our web site or you can get in touch with us. Our staff will let you know about the options available and talk through what they mean. No one will pressurise you to take part, it's entirely up to you.



More about feedback of results:

www.bristol.ac.uk/alspac/participants/feedbackofresults

More about changing your mind:

www.bristol.ac.uk/alspac/participants/changingyourmind

EXPERT RESEARCHERS



The research is run by the University of Bristol by expert scientists; it works to help society, not for commercial interests.

Children of the 90s was started by Professor Jean Golding and is now run by Professor George Davey Smith.



Leading researchers from all over the world use the information you give us to study the causes of the most important health and social problems facing the world today. Understanding the roots of these problems will help us to prevent them in future generations.

Professor George Davey Smith took over leadership of Children of the 90s from Professor Jean Golding, who retired to concentrate on her research.

EXPERT SUPERVISION & APPROVAL

Independent experts ensure that all research undertaken using the data you provide is of the highest scientific and ethical quality. Researchers who want to use information collected by Children of the 90s must prove that their projects meet the highest standards.

Many people help us make sure Children of the 90s make the right decisions:

- ✓ The Children of the 90s Executive; a group of the senior researchers and managers from Children of the 90s.
- ✓ The Children of the 90s Ethics & Law Committee; a group of experts, study young people and parents who are there to protect your interests.
- ✓ All research to do with the NHS is looked at by an independent group who are there to protect your safety, rights, well-being and dignity. This part of Children of the 90s has been approved by the 'North West 5 Research Ethics Committee'.

HOW DID YOU FIND ME?

Whatever part you played in Children of the 90s in the past we want to give you the opportunity to play a full part in the future.

We used official records to find addresses for all of those who can take part in the project. If you don't want to take part that's fine, let us know and we will delete your contact details from our database.

If there is a mistake in our records, let us know and we will change it.



WHO PAYS FOR IT ALL?

Children of the 90s is part of the University of Bristol. The University gives Children of the 90s a lot of the support we need in order to run. We also get support from charities like the Wellcome Trust and official bodies such as the Medical Research Council.





ACROSS THE GENERATIONS

Children of the 90s are committed to discovering how influences on health and well-being are passed across the generations. Because of this an important part of the study's future will be to focus on other members of your family for example your parents, brothers and sisters.

Some of you are already starting your own families. We would also like your children to have the opportunity to be part of Children of the 90s in the same way that you have.

This is not something we are asking you or anyone else in your family to decide on now but, if you agree for us to stay in touch, it is something we'll discuss with you in the future.

THE FUTURE OF CHILDREN OF THE 90s

Children of the 90s are interested in you and your health across your whole life time.

People have busy lives and we want to make it as easy as possible for as many people as possible to take part in Children of the 90s in the future. So as well as continuing to run clinics and send out questionnaires, we're also looking at new ways to collect the information we need.

An important way we will gather information is to make more use of the large amount of data that is already collected on all of us. We do this through a process called "data linkage". Section 2 of this booklet tells you more about this so you can decide whether or not you want to take part in this way.

