



BEING A PART OF CHILDREN OF THE 90s

Pages **4-16** in the detailed information booklet explains everything you need to know to help you make the right decision.

First we want you to 'sign up' to take part in the future of Children of the 90s.

To do this we're asking for your permission to keep your contact details on our file so that in future we can ask you whether you'd like to fill in a questionnaire or come to our clinic to give us information about you.

Why do you want to know about my life?

- → By looking at the details of thousands of young people's lives Children of the 90s can make important health discoveries.
- Your information can make a difference and benefit the lives of people around the world

WHAT AM I SIGNING UP TO?

Signing up to this does not mean you have to fill in any of our questionnaires or come to our clinics; it just allow us to contact you in the future.



Our contact details are on the back of the folder.



HOW YOU CAN TAKE PART THE EASY WAY

There is more information explaining about this on pages 17-30 in the detailed information booklet.

With your permission Children of the 90s would like to follow your health and life events by linking to your official records; those held by the NHS, the education system and the benefits, tax and earnings department. For some of you this includes information about criminal convictions and cautions. We call this way of collection information 'data linkage'.

Data linkage gives us information that is difficult to get using questionnaires or at a clinic. Some of it you wouldn't even know, for example the precise dose of an antibiotic you were given as a baby.

If you are happy to do this what happens next?

- Sign the consent form
- We will do all the work to set this up
- No more forms to fill in about this No one will contact you about this
 - We will not provide the organisations who keep your records with any of the information you have given Children of the 90s
 - No researcher will see your name with your data
 - You can make a decision about each type of record separately



Taking part in the project is voluntary and you are free to withdraw at any time without giving a reason.

You will not be identified from the research - researchers do not see your name with your information - they just see your barcode ID number.

Every research project is checked to make sure it meets the highest scientific and ethical standards.

In the same way as a doctor who treats you is bound to keep your information confidential, Children of the 90s, and all the researchers we work with, are bound to keep your information confidential.

There are independent experts whose job it is to look at what we do and how we do it to make sure your rights are protected.

We do not do commercial research - all our research aims to benefit society and is not for profit. We are funded by the University of Bristol, charities including the Wellcome Trust and the British Heart Foundation and also the Medical Research Council.

George Deweyshill

Scientific Director, Children of the 90s

