Be a part of something special...

Help us shape the future
Using your patient health information and other official records.
Key facts to remember while thinking about this

Where our research is in the public interest we may be allowed to use information from your official records. Our important research relies on us having high quality and complete information on as many people as possible.

If you are happy for Children of the 90s to use your patient health information and other official records in this way then:

- You need not do anything else.
- Unless you object we will manage the rest of the process.
- You will not be contacted about this by the NHS or any other organisation.

If you are NOT happy for Children of the 90s to use your patient health information and other official records in this way then:

- Please let us know using the form we have included.
- You can send back the form saying no to one, some or all of the linkage options.

We are planning to collect information from routine records in the near future, so please let us know your decision as quickly as possible.
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What are you asking me to do?

Children of the 90s intends to use your patient health records and your other official records in our research.

Your patient health records contain detailed information about the care you have received from the NHS. This includes your GP records, records about care received in hospital, dental records or community care. We describe your patient health records in more detail on page 16 to 17. They also include your civic registration records (your birth, marriage and death certificate).

Your other official records contain information about your education and care you receive, who you work for, your earnings or benefits you may receive, the community around you and the natural environment you live in. For some of you this will also include information about criminal convictions and official cautions. We describe these records on pages 18 to 25.

Children of the 90s will keep copies of your records for researchers to use for as long into the future as is possible, potentially hundreds of years. This will give researchers the best opportunity to make the most out of the help you have given us.

Unless you tell us you do not want this to happen we will securely collect your information after identifying your records through a process called ‘data linkage’.

Expert supervision & approval

Before any data is released to researchers, they must prove that their request meets the highest scientific and ethical standards.

To guarantee this, we consult:

- The Children of the 90s Executive: a senior research and management team led by Professor Nic Timpson, our Principal Investigator.

- 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 called the Health Research Authority, who are there to protect your safety, rights, well-being and dignity. This part of Children of the 90s has been approved by the NHS North West Haydock Research Ethics Committee.
Who pays for it all?

Children of the 90s is part of the University of Bristol.

We are primarily funded by the University of Bristol, the Wellcome Trust and the Medical Research Council.

Collecting information from your records

A great deal of information is collected and stored about all of us in our official records.

This information gives a detailed picture of many aspects of our life, such as our health and our experience of work. For some it includes information about criminal convictions and cautions.

Children of the 90s can use this information alongside the information about you that we have already collected. We can study responses to questions about why people lead different lives and why some people’s experiences are positive whilst for others they are less so.

We ask these questions to find ways of improving all our lives.

What is ‘data linkage’?

The way we bring together all these different pieces of the jigsaw of our lives involves a process called ‘data linkage’. It allows us to accurately and confidentially collect information from your records.

There’s more about how this works in the next few pages.
Sensitive information

We use the information you provide us in questionnaires or at focus clinics to answer questions about people and the things that shape their lives.

This does not mean that we stereotype people. We also don't judge people or judge what they do.

So when we ask for sensitive information (about things like crime, mental health or ethnicity) it is because we want to use this information to help us understand why things are the way they are and use this understanding to help reduce ill health and unfairness.

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.

You are unlikely to receive any direct benefit as our research aims to improve the public good. The main benefit is the knowledge you’re making a difference.

Your records will include detailed information about you, some of which is very personal and sensitive. We promise to keep this information confidential, secure and only use it for our research.

Some benefits of data linkage

• Data linkage makes it easier for you to play an important part in the future of Children of the 90s. Unless you object to this use of your information, we will do the rest.

• Even people who have been very active in Children of the 90s in the past still have some ‘gaps’ in their information. Data linkage can help us fill these.

• Some of the most important information about us is not something we necessarily know or remember. For example how close our home is to sources of pollution.

• Some people find it very difficult to take part in projects like Children of the 90s due to particular difficulties with their health or social situation.

Data linkage is an easy way to make sure everybody who wants to can be included, so that our research is relevant to everybody.
How does data linkage work?

- To make sure we accurately identify your records Children of the 90s will use your personal details (e.g. name, address, date of birth, NHS ID number) to make an accurate link to the equivalent information in your records.

- Once the data are linked together we remove your personal details and replace them with a unique anonymous code number - like a barcode.

- Only Children of the 90s needs your personal details to make this link – the researchers running the investigations don’t need them and never see them.

- Children of the 90s will collect a copy of your records on a regular basis into the future. We will only stop doing this if you ask us to.

Why don’t you just ask me about these things?

We use ‘data linkage’ to get information that is difficult to collect using questionnaires or in focus clinic interviews.

Some of it you wouldn’t even know (for example the precise dose of an antibiotic you have been given) and much of it is very technical, you may not have been told all the details and the details you were told can be difficult to remember. ‘Data linkage’ is the best solution to this problem.
Changing your mind

This may seem like a big ask to you but we want to reassure you that as with all parts of Children of the 90s, you are free to change your mind at any time.

We will remind you from time to time about data linkage and how our researchers are using the information found in records.

This is important as we will use the information in your records in the ways we describe in this booklet unless you tell us you don’t want this to happen.

You can find a list of research using your linked records here: www.bristol.ac.uk/alspac/participants/research-using-your-records/

Making research relevant and accurate

For Children of the 90s research to be relevant to as many people as possible, it is essential that we include information from as many study members as possible.

Health records

It is important that you tell us if you don’t want us to access your patient information. We will respect your decision.

In circumstances where research is in the public interest and based on the advice of a committee of experts, the Secretary of State for Health may allow researchers to access information in health records without patient consent.

The Secretary of State has granted this permission to Children of the 90s providing we have told you we intend to use your information in this way but you have not objected to this. So please tell us if you don’t want us to link to your health records. We will always respect your decision.

Your other records and your right to object

These principles also apply to other kinds of official records we’d like to collect information from. Again it’s important that you tell us if you do not want your records used in this way.
Your patient health information

Children of the 90s aims to discover the causes of important health problems and the best way to treat and prevent them.

Much of the information that is most useful to Children of the 90s researchers is held in your health records.

Health records include those held by your general practitioner (GP). We are bound by the same rules of confidentiality as your GP. Your name is never linked to the information taken from your records when used by researchers.

Your patient health record may contain information some people find particularly sensitive, for example about mental health or sexual health issues. It also includes your civic registration records (the information from your birth certificate, any marriage certificate(s) you have and at some point your death certificate).

Your patient health information includes:

- Details of visits to your doctor, diagnoses made and any treatment you were given.
- If you’ve ever been to hospital; why you were there and what happened whilst you were there. This includes visits to accident & emergency, if you were admitted to hospital for care or if you received treatment as an outpatient (e.g. to see a specialist consultant or nurse).
- Eye tests, hearing tests and dentist records.
- Details of community care you may receive, whether it is for a particular illness or for reasons to do with your mental health.
- Specific information about you, such as your ethnic group.
Children of the 90s researchers are studying the things that influence our experience at school and the way this affects the rest of our lives.

If you went to college, university or undertake any training at work or adult education, it is important to see how the skills you acquire influence your working life. Information about these questions are particularly important to us in the current economic climate.

Schools, colleges, universities and work based training are run and monitored by different organisations. They keep records about your education and support which would be of great benefit to Children of the 90s research.

These organisations also keep records about your care and support, such as if you were in care or adopted. It is important that Children of the 90s know about any care you received, as we can then investigate the impact of different types of care and make sure everyone benefits from our research.

Your education records include:

- Your exam results.
- Information about your attendance.
- Information about support and care you received – for example if you have a special educational need or were in care.
- Courses/training that you are doing.
- Specific information about you such as your ethnic group or the languages spoken in your home.
Benefits and earnings records

Different government departments collect information about your work, earnings, tax and benefits. We can use this information to help us understand more about how:

- wealth influences health.
- people move from education to getting a job.
- people rely on different benefits and services.
- people plan for the future, for example through setting up a pension scheme.

Taking part in Children of the 90s and data linkage is confidential:

- This will not affect the benefits you may get.
- Nobody will find out information about your finances.
- Your employer will not know anything about this.

Your benefits and earnings records include:

- Where you work and the type of job you do.
- How much you earn.
- Any benefits you may get to help you out.
- How much you pay in National Insurance and tax.

It does not include information from your bank account(s).
Criminal convictions and cautions

Children of the 90s data helps to discover the causes of the most important health and social problems in society.

Crime impacts on all of us directly or indirectly. The Police National Computer (accessed through the Ministry of Justice) holds records of all criminal convictions and official cautions.

Most of you won’t have a police record. It’s just as important for us to collect information on those who don’t have a police record as those who do.

- This is not a way for the police to find out things about you they didn’t already know.
- No one apart from Children of the 90s researchers will find out if you’ve had contact with the police (and they don’t see your name).

Everyone has a different view on how society should be and the way people should live alongside each other. Children of the 90s researchers are in a position to look at these questions carefully and objectively. The answers we discover will hopefully influence things for the better for all of us.

Your criminal convictions and cautions records include:

- Details of any crime for which you received an official caution or conviction.
- Details of any decisions made by a court about a crime and the punishment you may have been given.
Information about your neighbourhood and the natural environment around you

Your natural environment can have important positive or negative influences on your health and wellbeing.

Some people find their community to be vibrant and welcoming, others may feel isolated. Some people may live in areas with obvious pollution – such as from road traffic or factories – while others may live in areas with hidden pollution such as radon gas. For some people walks in the countryside or sitting in city parks may bring feelings of wellbeing, for others playing sport at the local leisure centre has the same effect.

Children of the 90s wants to understand how your neighbourhood and the natural environment around you impacts on your health, wellbeing and the prospects for you and your family.

Data linkage to natural environment and neighbourhood information works in a similar way to your other records. The main difference is that personal information about places (such as your home, office or the school you went to) are used to link to the information.

Natural environment and neighbourhood information includes:

- Information about your community (crime figures, house prices, employment figures).
- Information about your home (insulation levels, house age, house price).
- Information about pollution around your home, neighbourhood and where you work.
- Information about services around you (for example distance to the nearest GP, parks, libraries and other facilities).
Keeping your information confidential

The information in your records will be securely copied from the system containing the information (e.g. the database used by your GP) to a secure research computer.

Only then can records data be used by researchers in their investigations but even then it can never be linked to an individual’s name.

Can you be identified from your information?

Your information can be organised so it is harder to identify you.

Children of the 90s makes sure this is done appropriately, and that researchers don’t use your personal information in their research. Information can be:

- **Personally identifiable.** For example, if you visit a Children of the 90s focus clinic then we know who you are when you give your data.

- **De-personalised.** This is where information does not identify you as a person because your identifiers (e.g. name, date of birth) have been removed, encrypted or changed (e.g. date of birth is changed to age in years). However the information is still about a single person so still needs to be handled with care.

- **Anonymous.** Where the information from many people are combined together into summary statistics and graphs.
Other personal information – such as the address of your home – can be changed in a similar way. Children of the 90s would not share information linked to an identifiable address – even where address information was crucial for the research (for example, when studying the impact of air pollution near your home on asthma). Any address information is de-personalised before use.

Information security

We are aware of the trust you place in us to keep your information confidential and secure.

To help make sure our processes are working well Children of the 90s is independently audited by Information Security experts every year. Since 2012 Children of the 90s has been certified to the ISO27001 Information Security standard – the global best practice standard for information security.

Data protection

How a person or organisation can or cannot use your personal data is set out in the UK’s Data Protection laws.

The responsibility for making sure your information is used within the law lies with the organisation that is responsible for handling your data. This is usually the organisation that collected it.

Information that you give to Children of the 90s

Children of the 90s (part of the University of Bristol) is responsible for the information you give us at a focus clinic or in questionnaires, we control how it is used in order to comply with your rights.
Information about you that we receive from your official records

The organisations that collect your information in these records (e.g. the NHS collects your health records) are responsible for this information and tell us what we can and cannot do with them. Children of the 90s (University of Bristol) will:

- Make sure that your records remain confidential and advise our researchers on how these records should be handled in accordance with the Data Protection laws in order to comply with your rights.
- Work together with the official organisations which collect your records to protect your privacy.

Looking at your own records

Children of the 90s is not legally allowed to let you see what is in your official records. You do have the right to do this directly with the official organisations that hold your records, see our website for the details.

Our commitment to you:

- 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 conduct research for commercial gain – all our research aims to benefit society and is not for profit. We are primarily funded by the University of Bristol, the Wellcome Trust and the Medical Research Council.

Professor Nic Timpson
Principal Investigator of Children of the 90s
Any questions, problems or complaints?
Do you want to go through this with somebody?
Feel free to get in touch

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Have we got any of your details wrong?
Please update your details on our website at
www.bris.ac.uk/alspac/participants/update-your-details/

LARGE PRINT COPY
If you’d like a large print copy then please get in touch.

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