

Be part of something special...



Help us shape the future

Using your official health, education
and other digital records

Children of the 90s would like to use your official or digital records in our research. We call this type of research 'data linkage'.

Your digital records contain information about the healthcare you've received in hospital or at the GP, your dental records or any community care you receive. There are also civic registration records – these are your birth, marriage and death certificates.

You will have official records that contain details of your education, any care you receive, who you work for, your earnings, any benefits you receive or your interactions with the justice system. They may provide information about your local community and the natural environment around you.

Within these digital records lie many important details about your lifestyle, health and work. For some it includes information about criminal convictions and cautions.

Children of the 90s would like to access and securely keep copies of your digital records for researchers to use. This important data will build a detailed picture of you, your health and wellbeing and the environment in which you live.

This data will help us learn more about the causes of illness and disease and help future generations.

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How can I take part?

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

- **You don't need to do anything**
- We will manage the rest of the process in a secure, anonymous way
- 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 digital records in this way then you NEED to tell us:

- Please let us know using the Data Linkage Decision Form here <https://q.childrenofthe90s.ac.uk/linkageconsent> or via the QR code below
- You can say '**NO**' to one, some or all of the options.

Whatever you decide about consenting to data linkage with official and digital records, this will not affect your participation in other aspects of the Children of the 90s, such as attending our clinics or completing questionnaires.



Key points to remember

High quality research relies on having high quality, detailed health information about as many people as possible. The more representative our data is, the more we can learn about health and wellbeing. For example, if we struggle to get enough data on men's health, we can use NHS records to fill in these gaps and help us understand it better.



What is data linkage?

Data linkage is when we connect your digital records with your clinic and questionnaire data like pieces of a jigsaw, in order to build a detailed picture of you and your health.

We are permitted to use information from your official records as our research is in the public interest. We collect data from different sources, securely and confidentially, using your NHS number for health records, your pupil number for education data or your address for environmental factors.



First, we identify your records using your personal details (such as your name, address, date of birth). We protect your personal details extremely carefully so that just the minimum amount of data is shared. If it's necessary to move your data, we make sure it is:

- Encrypted to a high level
- Password-protected
- Sent through a Secure File Transfer system meaning no one else can access it.

Nobody can be identified

Once your digital records have been linked with your data, we remove any personal details and replace them with a number, your unique study ID. In this way, no one can be identified at any point.

All identifiable aspects are removed before data is released to researchers, so they never have access to your personal details. For example, if a researcher is investigating environmental data, then they just use data values relating to the area where you live and your unique study ID.

Our research is ethically approved

Researchers wanting to access your data must prove that their study meets the highest scientific and ethical standards. To do this, we consult:

- Our Ethics and Law Committee: a group of experts including participants who are there to protect your interests
- Our Executive: a senior research and management team led by Professor Nic Timpson, our Principal Investigator
- The NHS Health Research Authority whose role is to protect your safety, rights, well-being, confidentiality and dignity.

Your data is secure and protected

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

To keep our processes and data secure, Children of the 90s is independently audited by information security experts every year. Since 2012, we have been certified to the global best practice standard for information security, ISO27001.

We always respect your wishes

As with all our research, you are free to change your mind about taking part at any time. We will always follow your wishes about how we access and use your data. We will regularly update you on our data linkage plans and how researchers are using your data.

You can tell us you've changed your mind online at www.childrenofthe90s.ac.uk/our-commitment-to-you/changing-your-mind/. Find out more about our research at www.childrenofthe90s.ac.uk/research-using-your-records.

Why does it matter?

Linking to your digital records means we can get far more detailed and accurate information about you – your health, environment and lifestyle.

Some of this information would be difficult to get directly from you. Perhaps it is information that you just wouldn't know e.g. pollution levels on your street. Or it may be quite technical, such as the precise dose and type of antibiotic you were given as a child.

Often you may not have access to these details, or it's just difficult to remember. Linking to your official GP or healthcare records gets around these problems.

Data linkage also helps fill the gaps in our health data. Typically, in studies such as ours there are more women than men who take part. So if we can use digital records to fill in the missing information about the men, then we can learn far more about men's health.

Over time, people find it difficult to take part in Children of the 90s as much as they would like to. Perhaps because of family or work, health or social circumstances, or even geographical distance. Even people who enjoy taking part and who have done all our clinics or questionnaires will have some gaps in their memory.

Data linkage can fill in these gaps and make our data more representative and inclusive of everyone. It's a hassle-free way for busy or long-distance participants to continue to play their part in Children of the 90s.

Sensitive information

We will sometimes ask for sensitive information which relates to crime, mental health, or ethnicity. Our research aims to understand why things are the way they are and to find ways to reduce ill health and inequality.



The Five Safes

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

To do this we use a security method used by the Office of National Statistics (ONS) known as the 'Five Safes'.

- **Safe People** - researchers have to show that they have the technical skills to use the data. They must complete a training course and sign an agreement promising to protect the confidentiality of your data at all times
- **Safe Projects** - researchers need to show that their proposed research is an appropriate and ethical use of your data. It must deliver clear public benefits. They must publish their results to enable use, scrutiny and further research
- **Safe Settings** - researchers can only analyse data on our systems. We use a Trusted Research Environment, where they have no access to email or the internet. Data cannot be removed and access to it is taken away when the research is complete
- **Safe Outputs** - once researchers have completed their work they need our team to check their results. We check them to ensure that the outputs, tables and charts they may want to publish cannot identify any individual person. Only then are the results sent to the researcher
- **Safe Data** - with all the above, we de-identify the data. We do this by removing names, addresses and any other details that would directly identify an individual person. We do this before we make them available for any analysis.

Which digital records do we want to link to?



Patient health records

Health records include those held by the NHS and your GP. This information can help researchers seeking to discover the causes and consequences of illness and disease. 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 sensitive information for example about mental health or sexual health issues. It also includes civic registration records such as birth, marriage and death certificates.



Your patient health record includes:

- Your GP appointments, diagnoses made and any treatment you were given
- Your hospital visits: why you went and what happened while you were there. Including visits to accident & emergency, hospital stays or outpatient care (e.g. to see a specialist consultant or nurse)
- Eye tests, hearing tests and dental 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.



Education records

Our researchers study experiences of school and how 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 and health.

Schools, colleges, universities and work-based training are run and monitored by different organisations. Your education records can greatly benefit our 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 knows about any social 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.

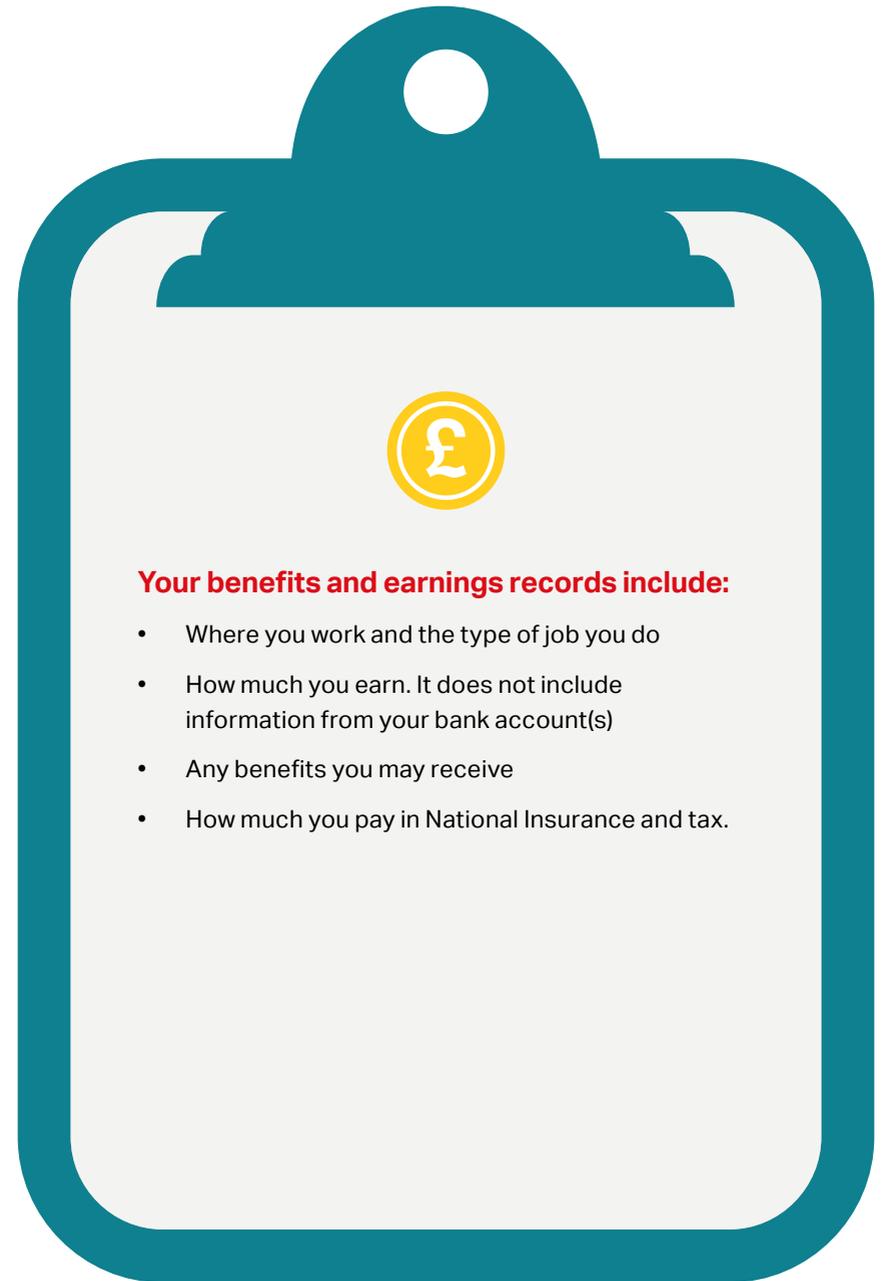


Benefits and earnings records

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 and wellbeing, how people move from education to getting a job or rely on different benefits and services. It also will tell us more about how people plan for the future, for example through setting up a pension scheme.

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

- This will not affect any benefits you may get
- Nobody will find out any information about your finances
- Your employer will not find out any information you give us.



Your benefits and earnings records include:

- Where you work and the type of job you do
- How much you earn. It does not include information from your bank account(s)
- Any benefits you may receive
- How much you pay in National Insurance and tax.



Police and justice records

Crime impacts on all of us directly or indirectly; there are victims, witnesses, suspects and those cautioned or convicted. The Police National Computer (accessed through the Ministry of Justice) holds records of arrests, criminal convictions and official cautions. Local police records can also hold information on victims and suspects.

Most of you won't have a police record, but it is 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 researchers will find out if you have had contact with the police.



Your police and justice records may 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
- Details of any crimes to which you may have been thought to be connected, possibly as a victim, witness, suspect or other association.



Your neighbourhood and natural environment

Your natural environment can have an important positive or negative effect on your health and wellbeing. We want to understand how your neighbourhood and the natural environment around you impacts both you and your family.

Linking to information about your natural environment and neighbourhood 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 data. Your address will never be shared with reserachers.



Your environmental 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).

Working with external researchers and organisations

The value of Children of the 90s is recognised internationally. We work with approved researchers from around the world using your questionnaire and clinic data to answer their research questions.

We will also share access to your linked data to approved researchers from outside the University of Bristol to lead projects that might not otherwise be studied. We only share data that is relevant to their research question, but this does mean that for the time they are analysing this data they are data controllers – a technical status with very strict legal obligations.

We will still control their access to your data, and the researchers **MUST** work within our Safe Setting (our UK based Trusted Research Environment). We will ensure they can only see the minimum amount of your data they need to complete their project, and we review their research outputs to make sure nothing identifiable is contained within their publications.

They WILL:

- decide the research project question
- have access to some of your data
- direct the research using your data
- decide how your data will be analysed
- decide how the results from your data will be presented and published

They will NOT

- have access to your identifiable data
- be provided a copy of your data
- be able to make a copy
- be able to do unauthorised research



Connecting data with other studies

Studies like Children of the 90s are unique in science and help researchers understand how our genes, lifestyle and environment affect our health.

The UK is home to many different longitudinal studies like us that follow different groups of people, born in different regions, at different points in time. If we combine our data with similar longitudinal studies, it can lead to much greater scientific impact.

Studies like Children of the 90s can work together to answer priority questions about health and wellbeing. For instance, combining data on dementia or heart disease from many studies means researchers can access a larger dataset than any one study is able to provide.

- During the COVID-19 pandemic, data linkage collaborations were critical in helping researchers to study the disease and learn more about it
- We make access to our study samples and data as clear and easy as possible for researchers
- We work closely with lots of researchers and encourage collaboration
- The Children of the 90s and any other research collaborators will continue to honour your individual instructions on which areas of your data (e.g. health, education, environmental) you allow us to access through secure data linkage
- No identifiable details will ever be provided to any other study, or collaboration of studies.

Details of the studies that Children of the 90s are collaborating with can be found at www.bristol.ac.uk/alspac/participants/privacy

Can you be identified from your information?

Your information will 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 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. This is 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). The information is still about a single person so still needs to be handled with care.
- Anonymous. This is where information from many people is combined into summary statistics and graphs.



Other personal information – such as the address of your home – can be changed in a similar way. We would never 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.



Our staff supervise the use of your de-personalised information. We only allow approved researchers to access the information they need to conduct their research. Researchers must sign a legal contract, which requires them to keep your information confidential and secure, before accessing the de-personalised information.

Children of the 90s staff make sure the research findings are anonymous before they are made widely available.

What is data protection?

How a person or organisation can or cannot use your personal data is set out in UK data protection law.

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 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. They tell us what we can and cannot do with it. Children of the 90s (University of Bristol) will:

- Make sure that your records remain confidential. We advise our researchers on how these records should be handled in accordance with data protection law
- 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. However you do have the right to do this directly with the official organisations that hold your records.

Our commitment to you

- Taking part in Children of the 90s research 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 anonymous study ID
- 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, Wellcome and the Medical Research Council.

Thank you for contributing to one of the world's leading health studies and making life better for everyone.



**Professor
Nic Timpson**

Principal Investigator
of Children of the 90s



Any questions?

If you have any questions, please contact us at:

Children of the 90s, Oakfield House,
Oakfield Grove, Bristol, BS8 2BN.

Tel. **0117 331 0010** or **07772 90 90 90**

Email: **info@childrenofthe90s.ac.uk**

Please update your details at:

www.childrenofthe90s.ac.uk/update-your-details



Any feedback?

- If you have any feedback or questions about any part of your involvement with the study, please email **info@childrenofthe90s.ac.uk**.
- If you would prefer to raise any issues outside the study, please email the University's Research Governance Team: **researchgovernance@bristol.ac.uk**.