

Using your health and other routine records



Children of the 90s would like to follow your health and life events by linking to your official records, such as your patient records (e.g. those held by your GP or covering any hospital visits and care you have received from specialists or community health care providers).

Your official records also contain information about who you work for, along with any earnings or any benefits you may receive, the community around you and where you

live. For some people this may include information about criminal convictions and official cautions. We call this way of collecting information 'data linkage'.

Data linkage gives us information that is difficult to get using questionnaires or at a clinic. It enables important new scientific opportunities for Children of the 90s. We will not provide the organisations we work with (such as the NHS) with any of the information you have given Children of the 90s.

This leaflet explains why we want to do this, and what to do if you don't want us to use your information in this way. For more detail please see the enclosed booklet 'Be a part of something special'.



If you are happy for us to use your records in this way:

- We will do all the work to set this up
- There are no forms to fill in
- No one will contact you about this
- You can change your mind at any point



If you **do not** want us to use your records in this way:

- **You must tell us**
- You can decide about each type of official record separately
- We will ensure your records are not used in this way

Why 'data linkage' is so important

We understand that you only give us your information to enable scientific discoveries for the greater good. The research we do is increasingly complex as scientific understanding improves and technology allows us to study health and wellbeing in new and exciting ways. We need this data to maximise our chances of making these discoveries.

Data linkage is one of the ways in which we can do this. It helps in these important ways:

1. Children of the 90s data allows researchers to study patterns across a whole population of people – the families from in and around Bristol who had children in the early 1990s. We need as many of you as possible to take part to make sure our research is accurate and represents all parts of society. We know we have asked you to do a lot and many people have not been able to take part in everything. We also know that some people's health and other circumstances are a barrier to taking part. Data linkage is an easy way to take part.
2. Combining the information you give Children of the 90s with data from your official records brings new possibilities. It will allow us to collect information that you may not know (such as observations made about you and your care while you were treated in hospital) or information that is difficult to remember (such as precise doses of medicine you have been prescribed). Increasingly, databases of official records are being used for research and are producing important results. Linking records with information in a study like Children of the 90s offers new possibilities for science.
3. Data linkage allows us to look for patterns of information about changing health and wellbeing over time. For example in some people symptoms such as wheezing may progress into asthma, while in others it may not. Identifying patterns like this will help us to identify people at risk.

This work will use data provided by you during your care and collected by the NHS as part of their care and support.

#datasaveslives



Your Decision

For more information about data linkage and how Children of the 90s will use your information, please see the booklet 'Be a part of something special'.

If you object to this use of your information, please send back the enclosed form.

What happens if you send back the form saying no to some or all of the data linkage options?

- If you do not want us to link to your official records, we will respect your decision. It is your choice and you can say yes or no to any of the options. This will not change the way you take part in the rest of Children of the 90s.

What happens if you do not respond?

- Where our research is in the public interest we may be allowed to use information from your official records. We will continue to get in touch from time to time reminding you about how we are using your records.

Why are you not asking us to fill in a consent form?

We are taking this approach for three main reasons.

1. The greatest scientific benefit will occur if we can link to as many records as possible.
2. We have developed new technology which protects the confidentiality and security of your information (described in the detailed booklet).
3. The NHS uses this approach to improve healthcare and services through research and planning, so we aim to take this approach.



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.



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