ALSPAC PRIVACY NOTICE

Document Control

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<th>POL-ADM-0674-ALSPAC Privacy Notice</th>
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<tr>
<td>Author</td>
<td>Ross Robinson</td>
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Version History

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<th>Version</th>
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<tr>
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<tr>
<td>1.1</td>
<td>Ross Robinson</td>
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How we use your information

This privacy notice tells you what to expect when ALSPAC (Children of the 90s) collects information from its study participants. ALSPAC is a research project run and owned by the University of Bristol and the University is the data controller as defined in the Data Protection Act (the person who determines why and how personal data are processed).

It applies to information we collect from participants:

- Phoning, emailing or texting us
- Visiting our website
- Completing our questionnaires via our website
- Booking focus clinic appointments via our website
- Updating their contact details via our website
- Returning completed questionnaires, consent forms, reply slips or other written information
- Posting information on social media
- Collecting data from routine official records (for example NHS and other health records; school, college and university education records; economic records; criminal conviction and official caution records; environmental, census and local authority neighbourhood data)

It also applies to the way we handle, process and store your information in:

- Sending mail and email
- Storing questionnaires and consent forms
- Finding participants who we lose contact with
- Providing your research data for use in scientific research

We also provide you with further information on your privacy, confidentiality and anonymity in other parts of our website, and in the information we send you via post and email when we ask you to take part in clinics or questionnaires.

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 do research with the aim of commercial gain - all our research aims to benefit society and is not for profit

Changing your mind

If you wish to change the way you participate – or stop participating – in Children of the 90s you can do so at any time. More information on withdrawing from the study is available at http://www.bristol.ac.uk/alspac/participants/ethics/changingyourmind/. Please contact us via the details on our website to let us know.
Phoning, emailing or texting us

When you phone, email or text us we will verify your identity and ensure that you are a study participant before proceeding. Any information that you give us will be recorded in our contact management system (Arcadia) unless you request otherwise. We will also record relevant details (such as date or time) of the phone call, email or text message.

The University’s third party email provider is Google (Gmail). Please be aware that you have a responsibility to ensure that any email you send to us is within the bounds of the law. We use a variety of third party mobile network providers.

Visitors to our websites

When someone visits our website we collect standard internet log information and details of visitor behavior patterns. We do this to find out things such as the number of visitors to the various parts of the site to help us monitor and improve our site. We collect this information in a way which does not identify anyone. We do not make any attempt to find out the identities of those visiting our website. We will not associate any data gathered from this site with any personally identifying information from any source. If we do want to collect personally identifiable information through our website, we will be up front about this. We will make it clear when we collect personal information and will explain what we intend to do with it.

This notice is separate to, but supported by, the University of Bristol’s website privacy policy available at http://www.bristol.ac.uk/style-guides/web/policies/legal/privacy/.

Completing questionnaires via our website

When you login to the questionnaire portal of our website we will collect standard internet login information and details of visitor behavior patterns to help us understand how people are accessing different parts of the questionnaire. We will also use this information to decide if you have completed your questionnaire or not, and may then contact you to remind you to complete your questionnaire if you have not already done so.

If we do want to collect personally identifiable information through our website, we will be up front about this. For example, at the end of the questionnaire we will make it clear when we collect personal information such as your date of birth and will explain what we intend to do with it.

When completing your questionnaire online, all information you provide is confidential. Your research data and personal details are kept separately. No researcher will see your name linked to your research data.

Online questionnaires are administered on University of Bristol owned computer systems.

Booking clinic appointments via our website

When you login to the clinic booking portal of our website we will collect standard internet login information and details of visitor behavior patterns to help us understand how people are accessing different parts of the booking system.
If we do want to collect personally identifiable information through our website, we will be upfront about this. For example, when you book your clinic appointment online we will make it clear when we collect personal information such as your date of birth and will explain what we intend to do with it. When you book your clinic appointment online we will then use this information to contact you and update your personal records in our contact management system (Arcadia).

The clinic booking system is administered on University of Bristol owned computer systems.

**Updating your contact details via our website**

When you update your contact details via the online form on our website and hit ‘submit’, an email will be sent to the ALSPAC participation team who will then update your contact details on our contact management system. No information will be stored online.

The online form is administered on University of Bristol owned computer systems. The University's third party email provider is Google (Gmail).

**Returning completed questionnaires, consent forms, reply slips or other written information**

When you return an item to us in writing (for example a questionnaire, consent form, reply slip or written letter) we will treat this information as confidential. Your personal details will be kept separately from your research data. We will not pass your personal details to third parties without your consent except under the circumstances described below.

**How we will use your personal details**

We will keep your personal details confidential, and separate from your research data. Your personal details will not be shared with third parties except for certain service providers working on our behalf.

These third parties include:

- FileCentre and Commercial Transfer (for long-term storage of questionnaires)
- Gemini West and TopLink Envelopes (for printing and collating large mailings)
- Data 8 and FinderMonkey (for conducting searches of public databases when we lose touch with you)
- Shred-It (for confidential waste disposal)
- GVS Gift Voucher Shop (for printing and sending ‘thank you’ vouchers)
- Peak Answers (for making reminder phone calls)
- Three Cherries, Core Telecom and Voodoo SMS (for sending mass text messages)
- Ounce Technology (for administering online cognitive tasks)

We will only share your personal details with these third parties under strict conditions set out in a legally binding data processing agreement. This offers assurances about the use, access and security of any personal data disclosed and does not allow any onward disclosure or sales of personal data by the third party. We also use Royal Mail for posting questionnaires, invitations to take part and other correspondence.

Some research projects need information based on locations - such as where you live, where you work, which school you went to etc. Children of the 90s use addresses and
postcodes to produce new information - such as levels of air pollution near your home, or crime rates in your neighbourhood - which we then give to researchers. We do this in a way where the information researchers get cannot be linked back to the original address.

**How we will use your research data**

We will only collect your data with permission, for example by asking you to attend a clinic or complete a questionnaire. Once we have collected it, it will be processed for research use. It will be stored securely and confidentially. We will de-identify the research data, so you cannot be identified from it. We will then provide this information to researchers on request and only under strict conditions. This process is described in detail at http://www.bristol.ac.uk/media-library/sites/alspac/documents/research/Access%20Policy_v6.0.pdf.

**Posting information on social media**

ALSPAC maintains a number of social media presences, most notably on Facebook, Twitter and YouTube. Users of these social media presences should be aware that any information posted is covered by the terms and conditions of the respective site and is in the public domain. However, ALSPAC will not use this data for research purposes without asking for your permission. We will not attempt to use social media to collect your personal details.

Social media will only be used as a communication tool between us and you. We may store your Facebook URL, Facebook email address or Twitter username so that we may continue to communicate with you. This piece of administrative data will be stored securely in our contact management database, along with your other contact details that you have provided to us in the past.

Please be aware that you have a responsibility to ensure that information you post on our social media sites is within the bounds of the law.

**Collecting data from routine official 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. Children of the 90s researchers use this information alongside the information collected about you (for example, in questionnaires or at ‘focus’ clinics). Through doing this, researchers study questions about why people lead different lives and why some peoples life experiences are positive whilst for others they are less so.

Where we have permission Children of the 90s will identify and take a copy of parts of your official records; including those held by the NHS, the education system and the benefits, tax and earnings department. For some of you we will also collect information about criminal convictions and cautions. We call this way of collection information ‘data linkage’. There is a lot more information about data linkage on the Children of the 90s website at http://www.bristol.ac.uk/alspac/participants/playingyourpart/ and http://www.bristol.ac.uk/alspac/participants/playingyourpart/aboutyourrecords/.

Before we start linking to your official records we will write to you explaining how this works and giving you the opportunity to object. We have already done this for the young adults (those born in the early 1990s) in the study. We fully accept your right to decide that you don’t want us to access your records, and if you feel this way it is important that you tell us.
For more information about how we use your linked records please visit [http://www.bristol.ac.uk/alspac/participants/usingyourrecords/](http://www.bristol.ac.uk/alspac/participants/usingyourrecords/).

Please let us know if you have any questions or if you object to your records being used in this way. You can call us on 0117 3310033, email alspac-linkage@bristol.ac.uk or write to: Data Linkage Team, Children of the 90s, Oakfield House, Oakfield Grove, Bristol BS8 2BN.

We will not provide the organisations who keep your records with any of the information you have given Children of the 90s; for example, information from questionnaires or given at ‘focus’ clinic visits. Collection of this information by Children of the 90s will not affect the services you receive from government departments in any way. To make sure we accurately identify your records we will use your personal details (e.g. name, address, date of birth, NHS ID) to make an accurate link to the equivalent information in your official records.

**Complaints or queries**

ALSPAC aims to meet the highest standards when collecting and using personal information. We encourage people to tell us if they think that our collection or use of information is unfair, misleading or inappropriate. We would also welcome any suggestions for improving the way we handle your personal details.

This privacy notice is intended to be brief and clear, and does not cover every single way we handle your personal details in minute detail. However, we are happy to provide further information on request.

**Access to personal information**

ALSPAC aims to be as open as it can be in terms of giving people access to their information. Individuals can find out if we hold any personal information by making a ‘subject access request’ under the Data Protection Act 1998. If we do hold information about you we will:

- give you a description of it;
- tell you why we are holding it;
- tell you who it could be disclosed to; and
- let you have a copy of the information in an intelligible form.

To make a request to us for any personal information we may hold you need to put the request in writing to the address provided on our website.

If you agree, we will try to deal with your request informally, for example by providing you with the specific information you need over the telephone. If we do hold information about you, you can ask us to correct any mistakes.

**Links to other websites**

This privacy notice does not cover the links within this site linking to other websites. We encourage you to read the privacy statements on the other websites you visit.
Changes to this privacy notice

We keep our privacy notice under regular review. This privacy notice will be reviewed annually.

How to contact us

If you want to request information about our privacy policy you can contact us via the details on our website. Further information is also available in the University of Bristol’s Information Security Policy, available at http://www.bris.ac.uk/infosec/policies/.