

Avon Longitudinal Study of Parents and Children

ALSPAC

Key contact details:

To discuss any aspect of the ALSPAC study and enquire about data access, the team can be contacted on 0117 331 0167 or at alspac-data@bristol.ac.uk.

ALSPAC data dictionary:

ALSPAC (also widely known as Children of the 90s) is a world leading health study following the health and wellbeing of thousands of pregnant women and their families who were recruited between 1991 and 1992. The study explores all aspects of health and wellbeing, from obesity and liver disease to air pollution and mental health. The study was founded by Professor Jean Golding OBE and is now managed and directed by Principle Investigator, Professor Nic Timpson.

In the early 1990s more than 14,500 pregnant women living in Bristol (UK) chose to take part in a unique longitudinal birth cohort study, closely following the lives of mothers and their babies, to deepen understanding of how environment and genes impact health and wellbeing. As of 2025, there are three generations of participants taking part. Along with the children of the 90s and their parents, there are now a new set of babies who are the children of the children of the 90s. Already 2,500 of these children are enrolled in the study. Detailed information has been collected on these women, their partners, and subsequent children and grandchildren, using self-completed questionnaires, data extraction and medical notes, linkage to routine information systems and from hands-on research clinics. Participants contribute their health data in many ways, building a detailed picture of population health.

The ALSPAC resource is a treasure trove of data, allowing researchers to address the most pressing health issues of our time. The data is critical to understanding pathways of disease progression and helps to identify those most at risk. The multi-generational data allows understanding of how health and diseases develop, how risk factors change, biology changes, and what factors influence these. ALSPAC data is made available via an established research platform with a rich collection of data and samples. This platform provides an active, efficient and connected research infrastructure for new and exciting research.

Find out more about the [ALSPAC study here](#) and explore the [ALSPAC data dictionary](#) via the 'useful links' tab.

[Cohort profiles are also available](#) and have been published for all generations of the study. These profiles provide details on the recruitment and representativeness of the cohort.

Accessing ALSPAC data:

ALSPAC welcomes requests from all researchers wanting to access ALSPAC data and samples, whatever research area, institution, location or funding source. ALSPAC encourages and facilitates data sharing with all bona fide researchers (defined as a person with professional expertise to conduct bona fide research, and who has a formal affiliation with a bona fide research organisation that requires compliance with appropriate research governance and management systems).

A number of ALSPAC datasets can be accessed externally, for example some datasets are held by and accessible via the UK Data Service (UKDS). To see if an ALSPAC dataset

suitable for your research is available through UKDS, check out the [UKDS data catalogue](#). You will also find further information about UKDS and the data access pathway in the following [UKDS resource pack](#).

If the data you require is not available externally, then an ALSPAC data access request will need to be made via the 'Submit a research proposal' link on the [ALSPAC webpage](#).

Below is the data access pathway, outlined in 6 steps.

Step 1: Researchers are required to complete an online proposal form on the ALSPAC Online Proposal System, clearly outlining all data types, topics, participant groups and timeframes they wish to access.

Step 2: Once the proposal form has been submitted, it will be reviewed by the ALSPAC Executive Committee, who will assess feasibility.

Step 3: If approved, the researcher will be assigned an ALSPAC data buddy - a member of the Data Access Team who will assist the researcher throughout the duration of their project. The data buddy will provide details and support with making the formal data access request, which should include every variable wished to be used.

Step 4: If the formal data access request is approved the data extraction process, conducted by the ALSPAC team, will commence. Standard datasets are prepared within 2 weeks of all paperwork being completed and invoices settled. It is important to note however that some data may take longer to prepare.

Step 5: The researcher's assigned data buddy will provide the relevant paperwork and documentation for accessing the approved data or samples, and ultimately provide the requested dataset.

Step 6: Approved data users will be provided with login credentials for a project when the first dataset is ready to be accessed electronically via Secure Data Transfer. Data is only shared with applicants identified as data users on approved projects.

Tips and guidance on completing a successful data access request:

- The proposed research must be in the public interest and not being carried out for personal or commercial gain. This must be demonstrated clearly in the application.
- The proposal should have clearly stated aims and hypotheses and describe the relevant exposure, outcome and confounders that will be considered, justifying the data required.
- If you are planning a proposal to access biological samples you are strongly advised to discuss your plans with the laboratory team prior to applying. The team can be contacted at: bbl-info@bristol.ac.uk.
- The assigned data buddy will not provide statistical, methodological or other support without prior agreement and the relevant costs being covered.
- Any amendments to the original proposal must be submitted via the same online proposal system.
- If a researcher wishes to re-use a dataset that has already been provided for a previous project a new proposal is required.

User access agreements:

No ALSPAC data will be released, even to approved projects and researchers, until necessary paperwork has been completed, signed and returned. This may include but is not

limited to: Data Access Agreement (DAA), Data User Responsibilities Agreement (DURA), Data Management Plan (DMP), Material Transfer Agreements (MTA). Your data buddy will be able to advise and support with this. The DAA and DURA are briefly outlined below. Further information about [ALSPAC access agreements and documentation](#) can be found here.

Data Access Agreement (DAA): a legal document laying out the terms and conditions under which ALSPAC shares data. It is non-negotiable. It must be signed by the PI, the recipient's institution's legal signatory and ALSPAC's legal signatory.

Data User Responsibilities Agreement (DURA): the project PI and any member of the team who will directly access the data will need to adhere to a number of clauses regarding confidentiality in the ALSPAC DURA. It is the PIs responsibility that all staff are known to ALSPAC, have completed a DURA, and are made aware of, and are adhering to, their data usage responsibilities.

Cost of access:

ALSPAC receives funding from Wellcome, the Medical Research Council and the University of Bristol to support core activities. These do not extend to providing support for individual projects, therefore researchers will be expected to meet any and all costs relating to data access and provision.

Costs will be determined on a project by project basis and will reflect only the true costs to ALSPAC of providing the resources requested. This cost will vary depending on the types of data requested and the amount of time required to facilitate the request. Data will not be provided until all necessary paperwork is completed and an invoice has been settled.

Example costings range from £2,500 - £5,500.

Additional Information:

The ALSPAC Data Linkage Team offers a linkage service, conducting bespoke linkages to NHS, administrative and other digital records. For further details contact: alspac-linkage@bristol.ac.uk.

When a project is nearing its end date the assigned data buddy will be in touch to confirm plans to delete supplied dataset, and the return of any variables derived from the data along with appropriate documentation.

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