Privacy Notice

Cancer Survivorship Studies (British Childhood Cancer Survivor Studies (BCCSS), Teenage and Young Adult Cancer Survivor Studies (TYACSS))

University of Birmingham

Background and Overview

1. Data protection law, including the Data Protection Act 2018, or any Act which replaces it, and the General Data Protection Regulation, sets out how personal data (personal information identifying someone) may lawfully be processed (collected, used and shared).

2. The University of Birmingham is registered with the Information Commissioner's Office (ICO) which is the body that ensures that data protection law, including the Data Protection Act 1998, or any Act which replaces it, and the General Data Protection Regulation, is complied with by all those processing personal data. The ICO notification sets out the types of personal data the University of Birmingham processes and for what purposes. The University of Birmingham registration can be viewed at: https://ico.org.uk/ESDWebPages/Entry/Z6195856.

3. Details about your rights in relation to your data are set out on the University of Birmingham website page 'Data Protection – How the University Uses Your Data'. This also explains how to ask any questions you may have about how your personal data is used, exercise any of your rights or complain about the way your data is being handled. The rest of the key information you need to know about how we used your personal data is set out below.

4. The Data Controller for the personal data processed in relation to this study is the University of Birmingham. The Data Protection Officer is: Dr Nicola Cardenas Blanco, Legal Services, The University of Birmingham, Edgbaston, Birmingham. B15 2TT; email: dataprotection@contacts.bham.ac.uk; telephone: 0121 414 3916

5. The University of Birmingham, as Data Controller of the personal data that is collected, must issue a Privacy Notice to clearly set out, how and why it is using personal data as well as what personal data is being used.

6. The University of Birmingham, as Data Controller of the personal data that is collected, must provide adequate fair processing information regarding the purposes for which, and the manner in which, the personal data will be processed.

7. For the purposes of Cancer Survivorships Studies, the BCCSS and TYACSS cohorts (a group of individuals with shared characteristics) are defined as follows:

   BCCSS: individuals diagnosed with cancer under the age of 15 years, between 1940 and 2006, in England, Wales or Scotland, and who survived at least 5 years from diagnosis.

TYACSS: individuals diagnosed with cancer when aged 15 to 39 years inclusive, between 1971 and 2006, in England or Wales, and who survived at least 5 years from diagnosis.

The reason for studying these cohorts is to monitor the long-term health of these individuals with respect to outcomes that may have been directly influenced by their cancer or the treatment they received for it. These outcomes include new cancers, heart disease and lung disease; also, psycho-social outcomes including education, employment, and mental health.

To monitor these outcomes, the cohorts are linked at an individual level to the national registries for cancer and death and additional national population-based datasets (e.g. Hospital Episode Statistics for England (HES)).

In order to undertake the study, we have been provided with information about you from various sources. Some of this information is your personal data. Under data protection law, where we have processed your personal data which we have obtained from someone other than you, we have to provide you with very specific information about the source of that information, what we do with it and what your rights are.

What is our legal basis for processing your data?

8. The purpose and legal basis for the processing of these cohorts is to carry out research which we do in the public interest and processing is necessary for archiving purposes in the public interest, scientific or historical research purposes.
In particular the legal basis for the processing of these cohorts is covered under UK GDPR article 6.1(e): Public task: "the processing is necessary for you to perform a task in the public interest or for your official functions, and the task or function has a clear basis in law".

9. Also since we are processing special category data (health data) this is covered by UK GDPR article 9.2(j): "processing is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes in accordance with Article 89(1) based on Domestic Law which shall be proportionate to the aim pursued, respect the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject". This data will not be used to make decisions about you.

10. Further details are available under the UK General Data Protection Regulations (UK GDPR) article 6.1(e) and 9.2(j), which can be found at:
https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/lawful-basis/a-guide-to-lawful-basis/public-task/
https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/lawful-basis/special-category-data/

11. The data collected for these cohorts is individual level data relating to the cancer diagnosis. Each individual is routinely linked to the national cancer registries and national death registries where applicable. The information relating to cancer and deaths is provided by NHS Digital in association with the Office of National Statistics and the General Register Office (GRO) for Scotland and comprises date of cancer registration (month and year only)

and diagnosis, and date and cause of death. Further data collected will depend upon the outcome of interest (e.g cardiac disease) and the results of the linkage with the national resource (e.g. National Institute for Cardiovascular Outcomes Research).

12. The data for each cohort is split into two components linked by a unique numeric identifier assigned to each individual person in the respective cohorts. All of the personal identification information (e.g names, addresses, NHS numbers) has been removed from the cohorts and stored on encrypted electronic media in secure locations within the University of Birmingham. In the remaining data, event dates (e.g. date of birth, death of cancer diagnosis and date of death) which may enable the identification of an individual will all be offset (adjusted) by a specific individual number for each date. The removal of the personal identification data and the recoding of the subsequent data, results in a data set that is pseudonymised: - any information that could directly identify an individual has been removed.

    The only occasions where the separated datasets for each cohort are recombined (using their unique numeric identifier) will be for the purposed of linkage as described above in point 11. All such linkage will be subject to legal data sharing agreements between the parties concerned. The resulting linked data will have the personal identification information removed and any dates adjusted as described above.

    The encryption key for the electronic media and the offset values for the dates will be known only to members of the Centre for Childhood Cancer Survivor Studies (CCCSS) at the University of Birmingham who are responsible for the running of the Cancer Survivorship Studies.

    Under Article 17 of the UK GDPR individuals have the right to have personal data erased. However, removing information will limit our ability to conduct research. We are performing a task carried out in the public interest and processing is necessary for archiving purposes in the public interest, scientific or historical research purposes where erasure is likely to render impossible or seriously impair the achievement of that processing. Also we are not relying on consent as the lawful basis for holding the data. Please see for further details: https://ico.org.uk/for-organisations/uk-gdpr-guidance-and-resources/individual-rights/individual-rights/right-to-erasure/

Purposes for data processing

13. We collected and processed your personal data to conduct the study. More information about the study is provided here: https://www.birmingham.ac.uk/research/activity/mds/projects/haps/pheb/cccss

14. The numbers of the outcome of interest (e.g. cancers, and deaths) observed in the respective cohorts will be compared to the equivalent outcomes in the national datasets to identify whether there is an excess risk of the outcome of interest when compared to the general population.

15. To improve our measures of exposure to anti-cancer treatment by linkage to national chemotherapy and radiotherapy datasets.

16. To establish a system to monitor the risks of adverse health outcomes and related healthcare activity and cost among these survivors, and to determine how observed risks and costs compare with those expected from the general population to determine subgroups of survivors who experience substantially increased risk and who may place a higher demand on services.

17. Provide advice to national health authorities of subgroups of survivors with particularly high risks of specific outcomes for potential recall or other intervention.

18. To enable large-scale population-based investigations of the risks of a comprehensive spectrum of fatal and non-fatal adverse health outcomes to provide the most reliable and unbiased evidence available for:

- feeding back to, counselling, educating and empowering survivors;
- developing evidence-based clinical follow-up guidelines;
- preparing care plans for survivors
- providing educational material for health care professionals including GPs;
- evaluating risks as well as benefits of proposals for future treatment protocols;
- identification of low risk groups for potential discharge from hospital based follow-up;
- provide information to national health authorities, to guide levels of clinical follow-up needed by different specific subgroups of survivors;
- provide health economic evaluations from financial information recorded in hospital activity registers to compare the observed and expected costs relating to survivors.

Who will my personal data be shared with

19. Each national registry/database for which we have legal consent to link with.

How is the data stored?

20. The University takes great care to ensure that personal data is handled, stored and disposed of confidentially and securely. Our staff receive regular data protection training, and the University has put in place organisational and technical measures so that personal data is processed in accordance with the data protection principles set out in data protection law.

21. The University has an Information Security Management System based on ISO27001 with a range of controls covering the protection of personal information. Annual security awareness training is mandatory for staff and the University is accredited under the NHS Information Governance Toolkit, the Payment Card Industry Data Security Standard and is in the process of gaining Cyber Essentials Plus for defined services.

22. The data will be stored at the University of Birmingham which is registered under the NHS Data Security and Protection Toolkit (organisation code: 8HL72). The most recent assessment (2024-25 – version 7 – Standards met) was published on 09/05/2025 (https://www.dsptoolkit.nhs.uk/OrganisationSearch/8HL72).

23. The data will be stored on a file server in a locked, secure, specialised room with appropriate heating and ventilation. Access to the room is limited to UBHAM Information Technology personnel only with swipe card systems.

24. Access to the network is by a secure password.

25. All staff members are required to sign an undertaking of confidentiality.

How long will the data be held by the University of Birmingham?

26. In line with the Data Protection Act, the University of Birmingham will hold the personal data for no longer than is necessary to fulfil the purposes of the work outlined above. Current ethical approval has been granted until 23/02/2026. When funding to extend the analysis time period is no longer available the data will be archived securely at the University of Birmingham for 25 years. After the archiving timeframe has expired in the absence of funding has to undertake further analysis of the cohorts, the data will be securely destroyed.

Are changes made to this webpage?

27. This privacy notice is effective from 26th September 2025 and is reviewed where necessary. Any changes will be published here.