

The British Doctors Study REC 19/SC/0602

PRIVACY NOTICE

What is the British Doctors Study?

The British Doctors Study (BDS) is the world's first large study of the effects of smoking that began in October 1951, when a questionnaire on smoking habits was sent to all registered British Doctors. The results of the study established a convincing link between tobacco smoking, lung cancer, circulatory problems and death and substantially influenced national and personal decisions about quitting smoking.

The 1978 follow-up questionnaire sought information from all male doctors born in the 20th century about a wider range of characteristics including alcohol consumption and self-reported body mass index. At this time they were also invited to participate in the British Doctors Aspirin Trial (BDAT), a randomised trial of daily aspirin to prevent death from stroke, heart attack or other circulatory conditions.

How is my personal information collected for the BDS?

Information about participants in the British Doctors Study has been provided mainly from the questionnaires completed and returned by participants on a regular basis up to 2001.

Information for long-term follow-up to date including cancer diagnosis data and cause of death is by data linkage received from centrally held NHS health records- these are:

- NHS Digital for England and Wales
- Privacy Panel for Health and Social Care (PBPPHSC) in Scotland
- Statistics Research Agency (NISRA)
- National Cancer Registration and Analysis Service (NCRAS)

A minimum amount of identifiable data information (first and last name, date of birth, NHS number or CHI number in Scotland) will be shared with these NHS bodies by the University of Oxford (data controller) to link with individual data for those who have died and to provide cancer registration data.

What is the purpose of the data processed for the BDS?

The British Doctors study is looking at the effects of smoking to establish a convincing link between tobacco smoking and lung cancer and chronic lung disease. The data acquired from the British Doctors Aspirin Trial is to assess the long-term use of aspirin on stroke, heart attacks, vascular disease and all cancers. Therefore the long-term follow-up to acquire and process high quality information (data) received from NHS central health records will ensure complete, high quality data on outcome for analysis.

Is the information collected by the BDS secure?

The information received from NHS Digital, NHS Scotland (identifiable data) and the National Cancer Registration and Analysis Service - NCRAS (identifiable and special category health data) will be imported to a securely accessed computer by The University of Oxford and used solely for academic research purposes by the study team in Oxford. Researchers at Oxford

University will remain responsible for the security and validity of the information held and only named members of the BDS study team will have access to the data collected.

Before analysing this data (including information already provided by the study participants), personal identifiers would be removed. Importantly, whilst the information received is specific to each study participant, no individual person will be identifiable in any publication arising from this work.

Sharing the data

Any personal data that identifies you are collected and managed by the BDS team and will not be shared with anyone else, except to obtain health information about you from NHS central health records (see section above). It will be used only to allow us to carry out the long-term follow-up.

The British Doctors Study database will not be shared with organisations outside of the University of Oxford and only accredited researchers in the Nuffield Department of Population Health and the Nuffield Department of Clinical Neurosciences, University of Oxford will have access to these data. Anonymous results of the study may be made available to collaborators and relevant bone fide researchers according to the Nuffield Department of Population Health (NDPH), data sharing policy found at: <https://www.ndph.ox.ac.uk/files/about/ndph-data-access-policy-1.pdf>

How long will my data be held by the BDS?

The University of Oxford will hold identifiable, personal data about you for the duration of this follow-up including data linkage as described above until 31st March 2024. Anonymised research data (under the study Unique ID) will be retained up to 25 years after the 'end of the study'. This is from the date of last publication resulting from the study, following which annual reviews of retention of anonymised research data will be undertaken.

Who is responsible for the BDS data?

The 'data controller' is the University of Oxford and as such is responsible for processing and looking after all BDS data for research purposes. The University of Oxford will only process personal data as necessary to undertake research that is being carried out in the public interest.

The legal basis for processing and storage of personal data for the British Doctors Study and British Doctors Aspirin Trial is that it is a 'task in the public interest (Article 6 (1) (e) UK General Data Protection Regulation (UK-GDPR). In addition, a required condition under UK-GDPR to process special category (sensitive) personal data is met, for scientific research purposes (Article 9 (2) (j) UK-GDPR).

The legal basis under common law for processing confidential patient information without consent is Regulation 5 of the Health service (control of Patient Information) Regulations 2002 ('section 251 support') and the study has support from the Health Research Authority (on advice from the Confidentiality Advisory Group).

What are my data rights?

Data protection regulation provides you with control over your personal data and how it is used. When you agree to your information being used in research, however, some of those rights may be limited in order for the research to be reliable and accurate. Further information about your rights with respect to your personal data under the General Data Protection Regulation is available on the University of Oxford's Compliance webpage <https://compliance.admin.ox.ac.uk/individual-rights>

If you would like to contact us directly for more information about how we process and protect data collected for research, please email Dr Hongchao Pan at: hongchao.pan@ndph.ox.ac.uk or call +44 (0) 1865 743835 (between 9-4pm on weekdays) or email information.governance@ndph.ox.ac.uk
You may also write to:

MRC Population Health Research Unit, Nuffield Department of Population Health, Richard Doll Building, Old Road Campus, Roosevelt Drive, Oxford, OX3 7LF.

Complaints:

If you have further questions or are not happy with the way your personal data has been handled please contact the study team using the contact details above., Alternatively, you can contact the study sponsor on 01865 616480 or email ctrq@admin.ox.ac.uk.

If you are not satisfied with our response or believe we are processing your data in a way that is not lawful you can complain to the Information Commissioner's Office at <https://ico.org.uk/make-a-complaint/> or call their helpline on 0303 123 1113.

What if I want to withdraw from the study?

If you decide you do not want your study data to be linked in this way you are free to withdraw from this long-term follow-up at any time. This can be done by notifying the BDS study team by contacting Dr. Hongchao Pan at: hongchao.pan@ndph.ox.ac.uk or call +44 (0) 1865 743835.

Your rights to access, change or move your data are limited as the University of Oxford needs to manage your information in specific ways in order for the research to be reliable and accurate. You have the right to access any personal data that is held about you by the British Doctors Study team and the right to ask us to correct any inaccurate personal data we hold about you. You have the right to restrict or object to processing of your personal data.

However, if you decide that you do not want any more information collected about you by the British Doctors Study, the University of Oxford may be obliged by law to keep information already collected to ensure consistency and reproducibility of the study results. Rights to receive an electronic copy of the personal data held about you are also limited.

You may also opt-out of NHS data sharing. More information on this is found at <https://digital.nhs.uk/services/national-data-opt-out> or in Scotland at: <https://spire.scot/my-choices>