

Privacy Notice

A cohort mortality study of oil refinery and petroleum distribution workers

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.
4. The Data Controller for the personal data processed in relation to this study is the University of Birmingham. The Data Protection Officer is: Mrs CM Pike OBE, 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 this study, the cohort (a group of individuals with shared characteristics) is defined as individuals working in the UK oil refinery industry and petroleum distribution workers. The reason for the study is to monitor the long-term health of these individuals with respect to neoplastic disease (cancer) and mortality (death).

Data collected for the cohort

8. The purpose and legal basis for the processing of this cohort 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 this cohort is covered under 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”. Also since we are processing special category data (health data) this is covered by 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 Union or Member State law which shall be proportionate to the aim pursued, respect the essence of the right to data protection and provide for suitable and specific measures to safeguard the fundamental rights and the interests of the data subject”.
Further details are available under the General Data Protection Regulations (GDPR) article 6.1(e) and 9.2(j), which can be found at:
<https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/public-task/>
<https://ico.org.uk/for-organisations/guide-to-the-general-data-protection-regulation-gdpr/lawful-basis-for-processing/special-category-data/>
9. The data collected is individual level data relating to the employment history of the individual linked to the national cancer registries and national death registries where applicable. The information provided by NHS Digital in association with the Office of National Statistics and the General Register Office (GRO) for Scotland comprises date of cancer registration (month and year only) and diagnosis, and date and cause of death.
10. The data is pseudonymised, which means that any information which would enable an individual to be directly identified has been removed and replaced by a unique identifier (a large number). NHS Digital hold the key for the pseudonymised identifiers. This makes the possibility, at the University of Birmingham, of linking the data back to an individual employee or their employment records highly unlikely. We at the University of Birmingham cannot identify and contact the individual members of the cohort.
Under Article 17 of the 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/guide-to-the-general-data-protection-regulation-gdpr/individual-rights/right-to-erasure/>

Purposes for data processing

11. The numbers of deaths and cancers identified in the cohort will be compared to deaths and cancers in the general population to identify whether there appears to be an excess risk of cancers (overall and by specific type of cancer) and deaths (overall and by specific cause) in the cohort when compared to the general population.

12. The results of these analyses will form the basis of annual reports to the study funder, the Energy Institute (<http://www.energyinst.org>, registered charity number: 1097899). No outputs will be reported at individual record level only in aggregate format.
13. The findings of the study will help the UK Health and Safety Executive (HSE) and the EU Scientific Committee for Occupational Exposure Limits (SCOEL) in assessing whether current national and EU regulations provide adequate protection to workers exposed to benzene. This is an on-going review process and copies of the study reports will be sent to both organisations.
14. The results will also be published in a peer-reviewed, open access journal which will be accessible by the general public, academics and regulatory authorities.

How is the data stored?

15. The data will be stored at the University of Birmingham which is registered under the NHS Information Governance Toolkit (organisation code: 8HL72). The current version is 14.1 for 2017/18, organisation code 8HL72 (ASS/237997, score 76%).
16. 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.
17. Access to the network is by a secure password.
18. All staff members are required to sign an undertaking of confidentiality.

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

19. 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. In the first instance funding has been secured for this study to continue to 31/12/2020 to complete the objectives of this work proposal. After which if no further funding is available to extend the analysis time period the data will be archived securely at the University of Birmingham for 25 years. After the archiving timeframe has expired and no funding has been acquired to complete further analysis of the cohort the data will be securely destroyed.