Long-term outcomes of traumatic brain injury

STUDY INFORMATION

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Contact us:
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About

A study was set up in 1998 by the University of Oxford to explore the long-term outcomes of traumatic brain injury among veterans who served in the British military during the Second World War and Korean War. The study involved 3,484 former servicemen who participated in the programme from 28/02/1940 to 19/06/1987. The study cohort included 1,087 veterans who sustained penetrating brain injuries, 2,197 who sustained closed brain injuries, and 200 who sustained non-brain injuries.

This original study sought to assess whether different types of brain injury affect life expectancy and cause of death. This involved linking the study cohort with routine mortality data held by the Office for National Statistics (ONS). This study continued until 2003, when most of the cohort were still alive and the data gathered up to this point were never published.

Our new study picks up this original work and will extend follow-up for mortality data by at least another 20 years.

Who are we?

The original study was part of a large research programme coordinated by the University of Oxford. In 1940, a national Military Hospital for Head Injuries (MHHI) was established at St Hugh's College in Oxford. The MHHI treated more than 13,000 soldiers with head injuries during the Second World War and Korean War. In the following years, more than 3,000 veterans participated in long-term follow-up studies which were funded by the Medical Research Council (MRC). This research programme was co-ordinated by Dr Freda Newcombe and led to many advances in our understanding of brain injuries and brain function. A selection of these publications is listed below. Our new study is being conducted within the University of Oxford governance framework which ensures that our work is carried out to high scientific and ethical standards.

The University of Oxford is the sponsor for this study based in the UK and will act as the data controller for this study. This means that we are responsible for looking after your information and using it properly.

This study has been supported by the Health Research Authority, on advice from the Confidentiality Advisory Group (24/CAG/0094). This study has also been reviewed and approved by the Oxford C NHS Research Ethics Committee (24/SC/0201).

What information was collected in the original study?

The original study extracted the hospital numbers and brain injury information (e.g. date of injury, mechanism of injury, clinical status after injury, treatment) of all veterans who were in the MHHI records from 28/02/1940 to 19/06/1987. The original study team then cross-checked hospital numbers against research records to gather other data relevant to health or necessary for data linkage, where that data was recorded in the records (e.g. name, date of birth, place of birth, military rank, correspondence address, NHS/CHI/H&C number). To link these veterans' data with information on mortality, they needed to share some details (e.g. name, date of birth, place of birth, address, NHS/CHI/H&C number) with the ONS. If the veteran had died in the period up to 2003, the ONS sent the original study team the date and cause of death. After they received the data from ONS, they removed all identifiable information, e.g. name and military service number, to create a 'de-identified' data file to be used for statistical analyses.

What information are we collecting for the new study?

Researchers at the University of Oxford are now collecting updated information on mortality data for those in the original MHHI veterans study from NHS England, NHS Scotland, and the Northern Ireland Statistics and Research Agency (NISRA). We will use this information to update the original analyses. In future analyses, we plan to link veterans' data with NHS data on other health outcomes, for example, cardiovascular and respiratory diseases, and mental health problems.

Why is the study being updated?

Recent studies have revealed important insights into the long-term effects of certain types of brain injuries, especially concussion. However, we still know very little about other types of brain injuries, including the most severe cases which involve direct damage to the brain caused by injuries that penetrate the skull.

To address this, we will update and complete this original cohort study of long-term mortality outcomes following traumatic brain injury. This study will be the largest of its kind ever performed. The results will be used to inform brain injury management guidelines, which currently do not provide guidance for people affected by penetrating brain injuries.

How will we share the findings of the study?

This study is being conducted as part of a PhD program at the University of Oxford. It will therefore be used to fulfil an educational requirement and the findings will be published within the thesis. We also plan to publish the findings in scientific papers and we will publicise them in the veterans' and armed forces communities, e.g. by making them available for relevant newsletters and websites. Scientific papers will contain only anonymous, aggregated data (e.g. percentages and averages) presented as tables and figures. The scientific papers will not contain any data on individual veterans.

How long will we hold the data?

Personal data will be used solely for the purpose of performing data linkage, after which study members will be identified by their unique study ID. After secure transfer to the appropriate national registries, no personal data will be stored in any electronic study file or database. De-identified research data will be stored securely on University servers for 3 years, in keeping with University of Oxford Research data policy.

How do we keep information safe and secure?

The original paper-based study data has been transferred from secure storage at St Hugh's College to the University of Oxford. Where this information could identify original study members, the information will be held securely with strict arrangements about who can access the information. At St Hugh's College, all paper-based documents are held in a locked archive. At the University of

Oxford, the information will be managed securely. Personal information will be sent via secure electronic file transfer from the research team to NHS England, NHS Scotland, and NISRA for the sole purpose of data linkage. De-identified mortality data will be transferred back to the research team for analysis. Personal data will not be stored in digital files. De-identified data will be stored securely in digital files, and will only be used for the purpose of health and care research. It will not be used to make decisions about future services available to original study members, such as insurance.

What is the legal basis for holding these data?

Completing this study will involve sharing personal data with NHS England, NHS Scotland, and NISRA without the consent of veterans to whom those data belong. We have received support to conduct this study without consent from the Health Research Authority, on advice from the Confidentiality Advisory Group. This permission is given under Section 251 of the National Health Service Act 2006 (24/CAG/0094).

How can original study members access their own data?

We do not have permission to access source records (except for the specific information supplied to us for the original study and this study). Individual veterans can apply to access the same original sources that we used:

To obtain details about the MHHI and the subsequent brain injury research, contact the St Hugh's College Archive: https://www.st-hughs.ox.ac.uk/current-students/library/archive/

Rights of access

Original study members have the right to see the information we hold about them. Further information about rights with respect to your personal data is available at https://compliance.web.ox.ac.uk/individual-rights. The University's data protection officer can be reached at data.protection@admin.ox.ac.uk.

If you are a family member of a veteran and would like to order a copy of their death certificate, see the gov.uk website: https://www.gov.uk/order-copy-birth-death-marriage-certificate

How can an original study member object to their data being used?

Article 21 of the GDPR gives individuals the right to object to the processing of their personal data.

If you wish to object to your personal data being processed, please email your reason(s) to the Chief Investigator, Professor Gabriele De Luca: Gabriele.deluca@ndcn.ox.ac.uk.

If you decide you do not want your data to be linked in this way you can withdraw from this study, without affecting your current medical care, by contacting the study team, who would require personal identifiers to then inform NHS England, NHS Scotland, or NISRA that you no longer wish to be part of the cohort. NHS England, NHS Scotland, or NISRA will not provide us with data for anyone who has objected.

Complaints

If original study members have further questions or are not happy with the way their data has been handled, please contact the study team using the contact details below. Alternatively, you can contact the Research Governance Ethics and Assurance at rgea.complaints@admin.ox.ac.uk or on 01865 616480. You have the right to lodge a complaint with the Information Commissioner's Office (0303 123 1113 or www.ico.org.uk).

Information for researchers

We will not make any record-level data publicly accessible because we need to protect the confidentiality and security of the individual cohort members. You are welcome to contact us with proposals for collaborative research, which the investigators will consider on a case-by-case basis, and which will only occur as part of a legal collaborative agreement and after the collaborator has put in place the relevant research ethics, data protection, and data access approvals. Please contact the Chief Investigator, Professor Gabriele De Luca: Gabriele.deluca@ndcn.ox.ac.uk.

Project team

Dr Jonathan Attwood
Professor Gabriele De Luca
Professor Edward de Haan
Professor Nicola Fear

Selected open access publications

1. De Haan EH, Heywood CA, Young AW, Edelstyn N, Newcombe F. Ettlinger revisited: the relation between agnosia and sensory impairment. J Neurol Neurosurg Psychiatry. 1995 Mar;58(3):350–6.

2. Fortuny LA, Briggs M, Newcombe F, Ratcliff G, Thomas C. Measuring the duration of post traumatic amnesia. J Neurol Neurosurg Psychiatry. 1980 May;43(5):377–9.

3. Humphrey ME, Zangwill OL. Cessation of dreaming after brain injury. J Neurol Neurosurg Psychiatry. 1951 Nov;14(4):322–5.

4. Newcombe F, Oldfield RC, Ratcliff GG, Wingfield A. Recognition and naming of object-drawings by men with focal brain wounds. J Neurol Neurosurg Psychiatry. 1971 Jun;34(3):329–40.

5. Ratcliff G, Newcombe F. Spatial orientation in man: effects of left, right, and bilateral posterior cerebral lesions. J Neurol Neurosurg Psychiatry. 1973 Jun;36(3):448–54.

6. Russell WR. Disability caused by brain wounds. J Neurol Neurosurg Psychiatry. 1951 Feb;14(1):35–9.

7. Spalding JMK, Zangwill OL. Disturbance of Number-Form in a Case of Brain Injury. Journal of Neurology, Neurosurgery & Psychiatry. 1950 Feb 1;13(1):24–9.