Wolfson Centre for Prevention of Stroke and Dementia (CPSD)
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The National Young Stroke Study (NYSS) **REC: 24/NW/0003**

PRIVACY NOTICE

What is the purpose of the National Young Stroke Study (NYSS)?

The National Young Stroke Study (NYSS) is an observational study looking at risk factors and burden of stroke in those aged younger than 55 years in England. The aims of the study are to improve our understanding of strokes at younger ages and how best to prevent and treat them.

How is personal information collected for NYSS?

Clinical data from the National Clinical Research Network hospitals are provided for identification of eligible participants and information surrounding these events. Administrative follow-up will undertaken for up to 30-years following enrolment, by the study team based at the Wolfson Centre for Prevention of Stroke and Dementia.

The legal basis for processing and storage of personal data for NYSS is that: it is 'a task in the public interest' (article 6(1)(e)) and, that sensitive personal data is necessary for archiving purposes in the public interest, scientific or historical research purposes or statistical purposes (article 9 (2) (j), based on Article 89(1)).
The administrative follow-up will involve linking the information collected from medical notes at beginning of study involvement with NHS England and civil registration data to report the occurrence of other diseases, survival rates and cause of death. This work will provide information about how long people live following a diagnosis of stroke and whether they die from problems relating to this or something else. The aim is to help doctors and patients understand more about the condition and its ongoing effects.

The common law duty of confidentiality is met for participants through their consent to participate in NYSS. We have special permission to conduct NYSS without study-specific consent (i.e. link, transfer, process and analyse the data) from the Confidentiality Advisory Group. This permission is given under Section 251 of the National Health Service Act 2006 and its current regulations, the Health Service (Control of Patient Information Regulations 2002) (CAG reference number: [To be added]). This support will be relied upon for those eligible individuals from whom it was not possible to obtain consent but did not decline after being sent information about the study.

A minimum amount of identifiable data (first and last name, date of birth, NHS number) from individuals will be shared with NHS England by the University of Oxford (data controller) to carry out the linkage between the study data and civil registration data.

Mortality data (date and cause of death), from the Personal Demographics Service dataset, held by NHS England, will then be provided directly back to the study team. The mortality data are provided by NHS England on behalf of ONS and is sourced from civil registration data. As soon as the date and cause of death have been linked with the participants study information, any data that could be used to directly identify individuals (name, date of birth, NHS number) will be removed and data will be stored within a highly secure data archive with limited access for designated NYSS staff for the duration of the study.

Sharing the data
Any personal data that identifies individuals are collected and managed by the NYSS team and will not be shared with anyone else, except to obtain health information about them from NHS England (see section above). Data obtained from NHS England will not be shared with anyone outside the NYSS study team at the University of Oxford.

Anonymised research data may be shared with other organisations outside the University of Oxford for research to improve healthcare delivery, subject to appropriate agreements being in place and approval by the Principal Investigator- Dr Linxin Li.

Who is responsible for the NYSS data?
The University of Oxford is the sponsor and data controller, and as such is responsible for processing and looking after all study data. Only named members of the NYSS study team, the host organisation and sponsor will have access to the data collected as part of the study that is regularly monitored by the Principal Investigator and the study steering committee.

How long will data be held by NYSS?
The University of Oxford will hold the minimal personal, identifiable data about individuals included (first and last name, date of birth, NHS number) for up to 30 years after the study recruitment. Research data resulting from the study will not contain any personal data that could identify individuals. The current end date for recruitment to NYSS is December 31st 2026 but will extend beyond this date if further funding is secured.

What are my 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 UK General Data Protection Regulation is available on the University of Oxford's Compliance webpage at https://compliance.admin.ox.ac.uk/individual-rights
More information about NYSS, the research team and how we use personal data can be found at https://www.ndcn.ox.ac.uk/research/national-young-stroke-study or if you would like more information about how we process and protect data collected for research please contact us at the address above.

What if I want to withdraw from the study?
If you decide you do not want your data to be linked in this way you can withdraw without affecting your current medical care. Please contact the study team: Email *nyss@ouh.nhs.uk* or telephone 01865 231601 or write to us at the address above. The team would require your identifiers to then inform NHS England that you do not wish to be part of the cohort. NHS England will not provide us with data for anyone who has declined or withdrawn consent.

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 RGEA.complaints@admin.ox.ac.uk
You also have the right to lodge a complaint with the Information Commissioner's Office (0303 123 1113 or *http://www.ico.org.uk*).