

UKYSS

Patient Information Sheet

Introduction

You have been approached about taking part in this study because you have previously suffered a stroke under the age of 50 years old. A stroke occurs because of a blockage in a blood vessel taking blood to the brain (ischaemic stroke) or because of bleeding from a blood vessel into brain tissue (haemorrhagic stroke). In the UK there are over 100,000 strokes every year, with approximately 10% of these affect people between 18-50 years old. These are called young strokes. There is only a limited amount of information about the young stroke population in the UK.

What's the study about?

UKYSS is a study about people in the United Kingdom who have previously had a young stroke. The study is aiming to collect information about an individuals' risk factors, the tests done to look for the cause of their stroke, their treatment and how people have recovered physically and mentally after their stroke. The researchers will then use this information to look for common themes amongst young stroke patients and try to predict what may cause a recurrent stroke or future death. This will help to guide future treatment, research and provision of resources.

What would taking part involve?

A member of the research team will contact you (or already has contacted you) to explain the study. If you are happy to take part you will be asked to complete a consent form online. Following completion of this some further questions will appear about your life following the stroke for completion. This should take no more than 10 minutes. Upon receipt of the

consent form a researcher (doctor or research nurse/practitioner) will access your online hospital records to obtain information about your stroke risk factors, tests performed to make the diagnosis, your medical treatment and the cause for your stroke.

What are the benefits in taking part?

The study will not benefit you directly, but the information we obtain will help us to understand young strokes in the UK better and come up with strategies to research and prevent young strokes in the future.

Are there any disadvantages to taking part?

This study does not involve medication or procedures. However, we will be asking questions about your stroke and your current physical and/or mental health, but these will be no different to questions a stroke doctor would normally ask. You should initially consult your GP if you feel there are issues regarding your mental health.

What if I have any questions or concerns about the study?

If you have a concern about any aspect of this study, you should ask to speak to the local research team who will do their best to answer your questions on XXX. You can also contact the person in charge of the study on XXXX. If you remain unhappy and wish to complain formally, you can do this by contacting either your local Patient Advice and Liaison Service on [insert local details here] by contacting NHS Complaints Procedure. Details can be obtained from <https://www.england.nhs.uk/contact-us/complaint/>.

What if I don't want to continue with the study?

Participation in this study is completely voluntary and you can withdraw your consent to participate in the study at any time. Withdrawal from the study in no way affects your future healthcare or participation in future healthcare research.

If you withdraw from the study, we will keep and continue to use all your previously collected data up until that point, but ensure this information remains completely anonymous. We will, however not collect or contact you for any further data about yourself in the future.

What will happen to the data collected about me?

We will need to use information from you and from your medical records for this research study. This information will include your email address, telephone number and name held by your local hospital. This information will be used to do the research or to check your records to make sure that the research is being done properly. Anyone who does not need to know who you are will not be able to see your name or personal details. Your data will

have a unique code number instead. We will keep all information about you safe and secure.

Collected information will be entered anonymously into a database, where you will be assigned a unique number that will only be known to link to you by the research team at your local NHS hospital and the sponsor (Keele University). On the consent form there will be an option to be contacted in the future to gain information about your longer term health after your stroke. Any such research will have undergone the same approvals as outlined below. If you chose not to select this option it does not impact you taking part in this study.

Data collected in this study may be anonymously shared with other researchers to further help to understand young strokes. This is an important practice which allows scrutiny of this study against other research in the same area. All shared information will remain anonymised and no personal information will be shared. This will be optional on the consent form and if you chose not to select this option it does not impact you taking part in this study. We need to manage your records in specific ways for the research to be reliable. This means that we won't be able to let you see or change the data we hold about you.

Keele University will be the data controller and has legal accountabilities to ensure that you are compliant with the General Data Protection Regulation (GDPR) and new Data Protection Act. All of your collected information will be kept and stored at Keele University for 10 years.

Where can I find out more about how my information is used?

You can find out more about how we use your information:

- At www.hra.nhs.uk/information-about-patients/
- By contacting the research team in your local hospital
- Reviewing Keele University's Privacy Notice at:
<https://www.keele.ac.uk/privacynotices/privacynotice-researchparticipants/>

What will happen to the results of this study?

The results will be written up and form part of the Chief Investigators' PhD thesis. The aim will also be to publish the results of this study in stroke and/or neurology journals. You can also contact your local research team.

Who is organising and funding this study?

Keele University is the sponsor for this study. Your local doctor is not being paid for including you in this study. The study will begin in hospitals linked to the person in overall charge of the study. If funding is secured it will expand to hospitals across the UK. If this

does not happen or the target number of patients is not reached, the data collected about you will still be very valuable and be analysed to provide insight into young strokes in the UK.

Patient and Public Involvement

The documents used and information being collected in this study have been reviewed by a patient group comprising of patients that have had a stroke whilst young. This group will be consulted throughout the study and at completion of the study.

Who has reviewed this study?

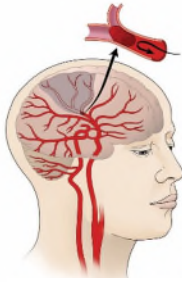
This study has been reviewed and approved by the South Central Berkshire Research Ethics Committee and gained approval from the health research authority.

How will I find out the results?

You may leave your email address on the consent form to receive results and updates as they occur. This will be kept and stored separately from any information collected as part of the research. The results will also be published in specialist stroke and neurology journals and presented at conferences.

Further information

If you would like further information about this study you can contact the lead for this study in your local hospital on (enter details here), over the overall lead for the study on XXXX



You previously suffered a stroke before the age of 50



The doctor would like to send you some information about a study relating to strokes in young people



They will ask for your consent to access your medical records...



...and complete a short 5-10 minute questionnaire



Researchers will then study the information collected to learn more about young strokes