

Information for patients and relatives

The purpose of the Australian Stroke Clinical Registry (AuSCR) database:

- AuSCR aims to provide data to support consistent high quality of care for patients and their families affected by stroke throughout Australia. Ultimately, it aims to ensure that all people may benefit from receiving the best possible care.
- Another aim is to provide a database to study the management and outcome of stroke in routine clinical settings. Stroke affects more than 50,000 people in Australia every year and it is one of the leading causes of death and disability in adults. Therefore, it is important for researchers to find the best evidence to develop strategies to prevent strokes from occurring in the first place, and to provide better treatments to improve the chances of recovery from stroke. In order for AuSCR to be successful we hope as many people as possible participate. We are asking you to participate in AuSCR by allowing us to document information that is relevant to your condition and experience.

AuSCR is a high-quality disease registry:

- AuSCR includes all patients with an acute stroke or a 'mini-stroke', called a Transient Ischaemic attack or TIA. It aims to improve the management and opportunity for recovery of people affected by stroke by collecting information from hospitals across Australia and patients at 3-6 months after stroke.
- By recording differences in the patterns of care and the results of treatments for this major health condition across the country, it is possible to improve the type of treatment given to so that all people may benefit and improve their chances of recovery after stroke.

AuSCR includes information on: each patient's name, date of birth, age, address, telephone number, Medicare number, patient hospital identity number, and the name of the hospital.

- This information is necessary to accurately link a person's hospital stay with any subsequent rehabilitation or health problems that they may have. This information allows us to collect further information regarding your health care needs from other linked hospital information systems so we know how well you have recovered.
- Information will be collected on a person's treatment, their medical care, any complications, and the diagnosis of the type of stroke.
- Details about the place of treatment and living arrangements at the time of discharge are also registered.
- No other personal information is recorded.

Follow-up information is gathered several months after the onset of stroke:

- All patients who are not known to have died will be contacted by telephone or mail at 3-6 months after the initial admission to hospital. At this time, some of the earlier information gathered is checked (e.g. current living arrangements) and questions about the current health status after stroke such as quality of life is evaluated.
- In addition, several questions are asked about the health and support that has been received following discharge from hospital.

How we will collect the information:

- We wish to record your details in AuSCR but you are not required to do anything. Your treating specialist and/or nursing staff will complete the form that contains your details during your time in hospital. The information will be entered into a specially designed password protected computer database after your discharge from hospital.

How we will keep the information confidential:

- All personal information is kept strictly confidential and cannot be used outside the Registry. Secure procedures are in place to protect all of the information and to keep it from being accessed by people outside the small number of research staff responsible for the registry at the University of Sydney and the National Stroke Research Institute.
- When a patient's details have been entered into AuSCR, the record will be given a specific number. All data analyses using patient data will be conducted only using the specific AuSCR number and not personal or directly identifiable information. This means that individual patients will not be identified in any reports that are produced and privacy and confidentiality will be maintained.

Risks and Benefits to you:

- There are no risks to your health by having your details in AuSCR.
- Your information is protected and we are not allowed to identify you by law.
- AuSCR will produce general reports on a variety of factors that influence the success of stroke care and rehabilitation. This will improve the quality of health services.
- It will not affect the way your treating doctors and team approach your treatment or long-term care.

Receiving Invitations from AuSCR Staff to participate in future research projects

- At follow-up, all patients will be asked if they are willing to be contacted in the future to hear about possible stroke research projects that they are eligible for.
- If you consent, AuSCR staff may contact you with the option of participating in a research study. AuSCR staff will forward you study information and you can then contact the researchers directly if you would like to participate or if you require more information. It is your decision to agree to or decline these offers.
- AuSCR will never provide your personal or contact details to anyone else (third parties) such as other researchers not associated with AuSCR or organisations.
- A decision on whether or not you wish to be contacted about future research projects does not affect your registration in AuSCR. You may choose not to be contacted about future research projects and you can still have your details included on the AuSCR database.

What to do if you don't want to be in AuSCR or change your mind:

- Participation is voluntary, but it is important that as many people as possible take part. In this way, we are able to have reliable information that is representative of all people who have a stroke to ensure appropriate improvements of stroke care in Australia.
- We understand, however, that not everyone is comfortable about having his or her personal details documented in a Registry. If you feel this way and do not want your details recorded, please contact the AuSCR Project Coordinator on telephone (02) 9993 4592.
- A decision on whether or not you wish to be involved in the Registry does not affect your treatment in any way.
- If you have any questions, concerns or require further information on the Australian Stroke Clinical Registry (AuSCR), please discuss these with your doctor or contact the AuSCR office.

What to do if you have concerns or complaints about the AuSCR database:

- The AuSCR project has been approved the Sir Charles Gairdner Hospital Research and Governance Unit
- If you have any concerns or complaints about the AuSCR database, please contact the AuSCR Project Coordinator on telephone (02) 9993 4592. Alternatively, you may contact the Ethics Coordinator who is the person nominated to receive ethics complaints from participants. You should contact them on 08 9346 2999 and quote **Trial No: 2009-006**.