

Information for patients and relatives

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

The Australian Stroke Clinical Registry is designed to collect information about people that have had a stroke in Australia. Stroke affects more than 50,000 people in Australia every year.

Hospital staff enter information in the Australian Stroke Clinical Registry about the hospital stay of stroke patients across Australia. This information may be used to develop better treatments plans to improve clinical care and thus the potential for recovery from stroke.

The Australian Stroke Clinical Registry will include all patients that have a stroke or a 'mini-stroke', called a Transient Ischaemic attack (TIA). Information will be collected during your hospital stay and again 3-6 months after discharge.

This Australian Stroke Clinical Registry is being overseen by Associate Professor Helen Dewey at Austin Health. The George Institute for International Health at the University of Sydney is responsible for storage and management of the information in the Stroke Registry.

The Australian Stroke Clinical Registry will collect information including:

Your name, date of birth, age, address, telephone number, Medicare number, patient hospital identity number, and the name of the hospital. Also the type of stroke you have had and your medical treatment and care, and any complications. This information is necessary to accurately link a person's hospital stay with any subsequent rehabilitation. 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. 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:

As a participant of the Stroke Registry you will be contacted by telephone or mail at 3-6 months after discharge from hospital. At this time, you will be asked questions about your current health condition since your stroke, plus some of the earlier information gathered will be checked (e.g. current living arrangements). You will also be asked several questions about the support that you have received since discharge from hospital.

How we will collect the information:

We wish to record your information in the Stroke Registry. After you have agreed to participate, 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. At this time you are not required to complete any forms or questionnaires.

How we will keep the information confidential:

All personal information is kept strictly confidential and cannot be used outside the Stroke 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. Once your information is entered into the Stroke Registry, the record will be given a number. 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 Stroke Registry. Your information is protected and we are not allowed to identify you by law. The Stroke Registry 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

During the 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 may suit you. If you consent, the Stroke Registry staff may contact you with the option of participating in a research study. The 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 organizations. A decision on whether or not you wish to be contacted about future research projects does not affect your registration in the Stroke Registry. You may choose not to be contacted about future research projects and you can still have your details included on the AuSCR study.

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 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. You can choose to have your initial hospital admission information entered into the Stroke Registry and not the follow-up information.

A decision on whether or not you wish to be involved in the Stroke 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.

The AuSCR will be open for approximately 12 months initially, however it is hoped to keep the registry open indefinitely.

What to do if you have concerns or complaints about the Australian Stroke Clinical Registry:

The AuSCR project has been approved by the Austin Health Human Research Ethics Committee.

If you have any concerns or complaints about the AuSCR study, please contact the AuSCR Project Coordinator on telephone (02) 9993 4592.

If you have any questions about the study, your health or any other study-related issues at any time during the study, please contact the study doctor or nurse. Or a medical practitioner can be contacted 24 hours by phoning Austin Health switchboard on 9496 5000 and requesting the Acute Stroke Consultant on duty be paged.

Study Doctor: Associate Professor Helen Dewey Telephone number: (03) 9496 2699

If you wish to contact someone, independent of the study, about ethical issues or your rights, or to make a complaint, you may contact: -

**Dr. Andrew Crowden
Chairman of the Austin Health Human Research Ethics Committee
Telephone (03) 9496 2901**