

What is the purpose of the Spine Registry?

The information from the Australian Spine Registry provides an important resource for patients, surgeons and the community about the likely benefits of spine surgery.

The Australian Spine Registry will:

- Allow your surgeon to follow your progress.
- Identify the best way to treat particular spine problems.
- Explore the usefulness and safety of different types of spine surgery.

What information is collected?

We will collect:

- Your name, age, address and contact details.
- The name of your surgeon and the hospital where you have had your surgery.
- Information related to your surgery.
- Some information about any other illnesses you may have or medications which could influence your care.
- Your progress after surgery at 6, 12 and 24 months.

Questions or Concerns?

If you would like more information about the registry please contact

📞 1800 277 001 (or 1800 ASR 001)

✉️ info@spineregistry.org.au

🌐 www.spineregistry.org.au

If you have any questions about the registry or about being a participant, you may contact the Manager of Melbourne Health Human Research Ethics Committee on (03) 9342 8530

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Welcome to the Australian Spine Registry

Information for Patients and Families



Introduction

The Australian Spine Registry (ASR) is an initiative of the Spine Society of Australia. The Spine Society of Australia is a non-profit organisation consisting of orthopaedic and neurosurgeons, researchers and other health professionals. It aims to encourage research and communication to improve the quality of care of patients who have spinal problems.

The ASR has been collecting information about spinal surgery since 2018 and works with surgeons in both public and private hospitals.

This information brochure is intended for you, the patient, and explains what is involved. This will help you decide about whether to be involved in the registry.

Please read this information carefully. Ask questions about anything that you do not understand or want to know more about. Before deciding whether to participate, you may wish to consult with a relative, a friend, or your local healthcare provider.

This is an opt-out registry. That means that your details will automatically be included in the registry unless you let us know that you do not want to participate. You can withdraw or opt out at any time by contacting us on Free call [1800 277 001](tel:1800277001) or by emailing info@spineregistry.org.au.

Your care will not be affected if you decide to opt out.

What does participation in the spine registry involve?

If you are happy to participate you do not need to do anything. Your surgeon and their staff will collect information from you either when you have appointments or from your medical records. You will be contacted by the Australian Spine Registry by email, letter or phone at 6, 12 and 24 months after surgery to complete two short questionnaires about your recovery after your operation. They should only take about five minutes to complete.

We collect your details to help us keep in contact with you. If you do not want us to keep your personal details, or if you do not want to participate in the registry, please tell your surgeon or let us know by telephoning Free call [1800 277 001](tel:1800277001).

What are the possible benefits?

The registry provides your surgeon with extra information about your progress after surgery by reviewing your questionnaires.

You will also be making a valuable contribution as the registry will be helping those who have spine surgery in the future.

The registry collects and studies anonymous data from patients to better understand the best treatments for different spine problems.

How is my data protected?

Privacy of patient information is taken very seriously. All patient information is safeguarded by the state and Commonwealth privacy laws and registry staff must comply with these strict privacy principles.

The Australian Spine Registry works with providers that have special expertise in safeguarding private information. All data is stored on servers within Australia in a high security environment.

Who has access to your information?

Your surgeon will have access to the information concerning their own patients to assist with ongoing care and provide feedback on progress.

Authorised registry staff can access certain information to help run the registry. They will not share your personal details with anyone outside the registry, including government agencies, insurance companies or court. Any reports shared will not include your identifying information.

Any research using Australian Spine Registry data must be approved by an ethics committee. By agreeing to have your information collected, you are also agreeing to its use in approved research.

Is the Australian Spine Registry approved?

This project is an initiative of the Spine Society of Australia and has been approved by the Melbourne Health Human Research Ethics Committee (HREC) (approval number HREC/16/ MH 93).

This project may link to additional Australian health databases such as, but not limited to, the National Death Index and Pharmaceutical Benefits Scheme. All requests for new information from any health database are undertaken with additional ethical oversight from the Australian Institute of Health and Welfare. All approvals will be published on the Australian Spine Registry public website (www.spineregistry.org.au).

All aspects of the ASR are monitored in accordance with:

- The Australian Government National Health and Medical Research Council's (NHMRC) National Statement on Ethical Conduct in Human Research (2023).
- The Australian code for the Responsible Conduct of Research (2018).

The statement has been developed to protect the interests of people who agree to participate in human research studies.

Do I have to take part in this registry?

Participation in the Australian Spine Registry is voluntary. You can choose to withdraw or opt-out at any time, and it won't affect your relationship with your surgeon or treating hospital.

Can I access registry information kept about me?

You can access the data kept about you at any time by contacting your surgeon or the registry.