

111 call, ambulance arrival time etc.) to the NZSCIR. This identifiable information is used to cross check processes for accuracy and quality.

Researchers with ethical approval may request NZSCIR identifiable data. Using this type of information allows NZ based researchers to compare NZSCIR data with other health data. Researchers must hold data securely and cannot publish individual level identifiable data.

As an international site of a Canadian based registry, overseas researchers may request NZSCIR data. These researchers need to conform to NZ Ethics standards and gain the appropriate approvals.

What are the possible risks?

Any unauthorised access or privacy breach is considered very low risk. The advanced security measures and rigorous ethical processes ensure data is held securely.

Do I have to take part?

No. Your participation is entirely your choice. If you decide not to take part, this will NOT affect the services or care you receive.



I would like to take part in the study, what do I do next?

The Registry Coordinator will visit you with a consent form and can answer any questions you may have about the registry and your participation. Thank you for your involvement.

Further information

If you have any questions, please feel free to review the NZSCIR Information Booklet and discuss your queries with the Registry Coordinator.

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NZ Spinal Cord Injury Registry
Te Rēhita Whara Aho Tuaiwi ā-Motu



Te Whatu Ora
Health New Zealand
Waitaha Canterbury

Te Whatu Ora
Health New Zealand
Counties Manukau

Please visit these websites for more information and reports

NZSCIR:
www.nzscir.nz

Praxis Spinal Cord Institute
(previously Rick Hansen Institute):
www.praxisinstitute.org/research-care/key-initiatives/national-sci-registry

Information Booklet Summary

New Zealand Spinal Cord Injury Registry (NZSCIR)

What is the purpose of the NZSCIR?

The NZSCIR collects information about people with a new spinal cord injury or impairment (SCI) in NZ to help improve treatment and care. Basic statistics are collected to help SCI services track how many people have a SCI, their causes, the severity, treatments and outcomes, helps answer clinical questions, aids research and service planning, as well as identifying and understanding any gaps in care and services.

How is the NZSCIR designed?

The NZSCIR collects basic information to accurately record how many people in NZ have a SCI in a year covering:

- demographics – such as age, gender and ethnicity
- some limited information about your SCI, such as cause (like a fall, a car accident, infection or tumour) and if you have had surgery.
- where you received treatment for your SCI

This information is collected from your medical records and entered into the national registry. The information is used by the Auckland Spinal Rehabilitation Unit at Counties Manukau Health, and the Burwood Spinal Unit in Canterbury, to improve patient care.



As well as the information already collected, the NZSCIR asks for your consent to collect more information. This helps us improve our understanding of SCI and treatment. Participation is voluntary.

Māori partnership

NZSCIR has a partnership with Te Ao Mārama Aotearoa Trust (TAMA). This is an independent group which sits alongside the Manatū Hauora Ministry of Health providing a voice for Tāngata Whaikaha (Māori persons with lived experience of a disability). It allows the NZSCIR to kōrero to support the disability sector and take necessary steps to achieve equity. It also helps guide the NZSCIR with tikanga and building partnerships.

What will my participation in the NZSCIR involve?

Hospital data collection

If you agree, we will collect additional demographic information from you. The Registry Coordinator will visit you to complete two questionnaires prior to discharge. The initial interview may take 5-15 minutes, and covers information like your education level, height, smoking history, questions related to your living situation and employment. You may refuse to answer any questions that you are not comfortable with.

Further details about your SCI, treatment, complications and rehabilitation will also be gathered from your clinical records.

The discharge interview may take 15-25 minutes and asks you about pain, function, and what services you have received during your stay.

Follow up data collection

After you have been discharged, we aim to contact you periodically to complete a questionnaire related to your health and quality of life. This can be by phone, mail, email link to a secure website, or in person. Follow-up data is important as it allows us to see how participants are doing in the community. Services can then see how to improve, whilst tracking changes in the SCI population that occurs over time.

Security and storage

Your identifiable information is held on a secure, cloud-based storage platform based in Canada. Canada abides by strict privacy requirements which are as secure as in NZ. Access to this data is highly restricted. Decisions about the use and access of this data can only be made by the NZSCIR which is governed by NZ ethical approvals.

If you agree, your information is stored in the registry indefinitely. You can request to see this information at any point. If you take part in the NZSCIR, you may withdraw at any time without giving a reason. All data collected up to the point of your withdrawal will be kept in the database for analysis, but no further data will be collected or entered.

What happens to my information?

Your confidentiality is respected. Protecting your privacy is important. Any publicly available reports (such as an annual SCI report) or publications from the NZSCIR are de-identified and grouped to avoid individuals being identified.

Identifiable information is any data that could identify you (e.g. your name, date of birth, or National Health Index number). NZSCIR Coordinators and clinicians already involved with your care have access to your identifiable information to ensure the correct data is being entered correctly.

The NZSCIR has electronic **dashboards** where information can only be accessed by the NZSCIR Coordinators. Dashboards are used to view and analyse information across the NZSCIR. Limited information can be given to researchers or clinicians to answer clinical questions, help determine if research is feasible, and contribute visual information to presentations.

Information from the NZSCIR is shared with researchers, clinicians and service providers through a **Data Access Request** process. Strict rules are in place to ensure information is kept safe and used appropriately.

The NZSCIR works with St John to share data. St John provides ambulance data (date/time of injury, time of