**Australian Spinal Cord Injury Register (ASCIR)**

**Consultation: Towards a New Governance Model**

**Introduction**

The Australian Spinal Cord Injury Register (ASCIR) is a national database that was established by the Australian Institute for Health and Welfare (AIHW) in 1995, with all spinal units (SU) in Australia contributing data on incident cases of spinal cord injury (SCI) from that date. The ASCIR has been managed from within the National Injury Surveillance Unit (NISU) at Flinders University, under the guidance of a Board. The Board currently comprises the Directors of eight spinal units (see list below), Professor James Harrison (Director of NISU and the representative for the AIHW), John Walsh AM (who established the first Australian-based SCI register in 1986), and several other people with relevant knowledge and expertise.

**New South Wales**
- Prince of Wales Hospitals
- Royal North Shore Hospital
- Royal Rehabilitation Centre (Moorong)

**Queensland**
- Queensland Spinal Cord Injuries Service (Princess Alexandra Hospital)

**South Australia**
- South Australian Spinal Cord Injury Service (Hampstead Rehabilitation Centre)

**Victoria**
- Victorian Spinal Cord Services (Austin Health)
- Spinal Rehabilitation Unit (Caulfield Hospital)

**Western Australia**
- Sir George Bedbrook Spinal Unit (Royal Perth Rehabilitation Hospital)

The primary output of ASCIR to date has been the production of an annual epidemiological report on the incidence of SCI in Australia\(^1\). During the past three years the Board and NISU have reviewed the register and decided that it should be changed so that it can support a wider range of functions. These are (1) a clinical quality registry; (2) a platform for SCI research; (3) a system capable of assessing health and well-being over time of people living with SCI; and (4) continuation of its current descriptive epidemiological function. In 2011, the Spinal Cord Injury Network (SCIN) funded a project undertaken with NISU and the ASCIR Board to engage a team from Monash University to undertake a scoping study for a redesign of ASCIR. To achieve these functions, the following recommendations were made in the SCIN report with regard to **Governance structure and data custodianship**:

1. A revised governance structure is required including representation from clinicians (medical and allied health), researchers and associated peak bodies (e.g. Spinal Cord Injury Network) ensuring appropriate regional representation and the appointment of an independent chairperson.

---

ii. Establish an appropriately constituted Steering Committee to oversee the governance of the ASCIR, including the development of strategic direction and ensuring deliverables are met for the registry and funding bodies.

iii. Convene an appropriately constituted Management Committee to manage day-to-day aspects of the registry and ensure data quality measures are reported regularly.

iv. Terms of Reference for the Steering Committee and Management Committee need to be developed, including meeting schedules and membership policies.

v. The data access policy needs to be reviewed and updated as necessary.

vi. Identify data reporting procedures including peer review processes, feedback to spinal units and dissemination of findings to the wider public.

vii. Provide a detailed and agreed policy on the use of the registry for research purposes and the publishing of data through peer-reviewed publications\(^2\).

In 2012, the ASCIR Board tasked NISU to commence a consultation process through which a new governance model might be proposed. The remainder of this document proposes a new model of governance for the Australian Spinal Cord Injury Register which is being made available for comment.

The model presented here is based on the outline provided in the SCIN report. Its development to a more specific level has been informed by recognition of the special roles of the heads of SUs that provided data to the register, people who are the subjects of the register and of the formal custodian of the data collection. It has also been informed by recognition of predictable functional requirements (e.g. a need for a mechanism to ensure timely decisions on data release) and recognition that the operational arrangements should not impose a heavy burden in terms of person-time or funding.

---


Process for Consultation

This document and an invitation to participate is being sent to key stakeholders during December 2012 and January 2013 for information and comment. Requests will also be made for this documentation to be placed on websites such as the Spinal Cord Injury Network, the Spinal Research Institute and the Australian and New Zealand Spinal Cord Society.

This consultation period will close on Friday 25th January 2013. Responses will be collated by NISU and will inform a Proposed Model of Governance and Terms of Reference which will be provided to the current Board and the AIHW in late February 2013 for an out-of-session decision in mid-March 2013.

To assist NISU in compiling responses, we request that your feedback be framed as written responses to the following broad questions.

1. What elements of the proposed new model (outlined on pages 4 and 5) do you support?

2. What elements of the proposed new model do you not support? Please provide an explanation and suggest alternative arrangements.

3. Name any clinicians/organisations/people living with a spinal cord injury with whom we should liaise concerning the identification of potential Committee and Affiliate Members?

4. Would you like to provide further comments on any other topic(s) we need to consider?

Written responses should be returned to the National Injury Surveillance Unit (NISU) via email amanda.tovell@flinders.edu.au or by fax 08 8374 0702, no later than Friday 25th January 2013.

Further enquiries about this process may be directed to Prof James Harrison, NISU Director, via email nisu@flinders.edu.au or by telephone at 08 8201 7602.
Proposed model of governance for the revised ASCIR

The following three-level model of governance may be appropriate for an Australian Spinal Cord Injury Register (ASCIR) which continues to be a repository of epidemiological data (as initiated by John Walsh AM) and moves towards also being a clinical quality register (aligned with the Strategic and Operating Principles as outlined by the Australian Commission on Safety and Quality in Health Care\(^3\)), a platform for research and a system capable of assessing the health and well-being over time of people living with SCI.

### Level 1: Data Provider and Custodian Committee

**Membership composition:**
- 3-5 data provider representatives nominated or elected by all participating spinal units
- ASCIR Data Custodian, currently this is the Australian Institute of Health and Welfare
- Data management representative - Director, AIHW National Injury Surveillance Unit
- 1-2 Registrant representatives - a person living with a SCI who is included in the registry (by nomination).

Executive positions should include a Chair and Deputy Chair. If New Zealand sites were to elect to participate in ASCIR, then the positions of Chair and Deputy Chair of the Australian and New Zealand Spinal Cord Injury Register (ANZSCIR) should have representation from each jurisdiction.

**Example of responsibilities:**
- Oversee and facilitate case flow from sites to NISU/ASCIR
- Approve inclusion/exclusion of data elements to be collected
- Identify and approve sensitive data which can be released to all sites for comparability
- Review and authorise research program requests related to ASCIR
- Develop and oversee policies relating to ethics, consent, data release, etc.
- Provide membership and oversight of the Data Release Subcommittee.

**Meeting schedules (and methods):** Monthly or bi-monthly, mostly virtual with a minimum of one face-to-face to coincide with the Australian and New Zealand Spinal Cord Society (ANZSCoS) Annual Scientific Meeting (ASM).

---

Data Release Subcommittee

Constituents: 2-3 members and ASCIR Data Manager or their delegate

Example of responsibilities:
- Provide prompt review of requests for data release
- Advise Approval, Declined or Referred to Full Committee status
- Action Approved requests
- Provide a quarterly summary report to Data Provider and Custodian Committee
- Provide an annual summary report to Advisory Committee and Affiliated Members.

Meeting schedules (and methods): As required, and quarterly (virtual).

Level 2: Advisory Committee

Membership composition:
- Chairperson
- All data providers and custodians
- Representative(s) from insurance groups (e.g. Motor Accident Commission, WorkCover)
- Representative(s) from the National Disability Insurance Scheme
- Representative(s) from consumer and advocacy groups (e.g. Spinal Cord Injury Network)

Example of responsibilities:
- Review dataset annually and advise possible inclusions or exclusions
- Review annual summary of data requests and advise any concerns/ideas
- Review protocol for access to access annually and advise any concerns/ideas.

Meeting schedules (and methods): 6 monthly (one virtual and one face-to-face Annual General Meeting to be scheduled prior to the annual face-to-face meeting of the Data Provider and Custodian Committee at the ANZCoS ASM).

Level 3: Affiliated Members

Membership composition: Any interested persons or groups.

Example of responsibilities: None specific. Affiliated Members will be invited to participate in surveys and workshops where relevant to provide feedback on ASCIR operations.

Meeting schedules (and methods): No specific schedule. Affiliated Members will receive an email alert advising release of Spinal Cord Injury Australia series, and an annual electronic newsletter from ASCIR. Affiliated Members will also be invited to attend the Annual General Meeting.