Appendix 1

Structure and operation of ASCIR

The Australian Spinal Cord Injury Register (ASCIR) is a national register of incident cases of spinal cord injury that occurs in Australia and overseas to Australian residents. The ASCIR operates as a collective venture of the Directors of all 6 spinal units in Australia and the National Injury Surveillance Unit (NISU), an external Unit of the Australian Institute of Health and Welfare (AIHW). The ASCIR is funded as part of the NISU program which is managed and operated by the Flinders University Research Centre for Injury Studies (RCIS).

ASCIR governance and management is under the auspices of the ASCIR Operation and Management Board. The current members of the Board consist of the following: the Chair (a spinal unit Director), AIHW Data Custodian for ASCIR data, three spinal unit Directors, two spinal unit physicians/researchers, and two other members who have experience in the operation of registers.

This management structure optimises the operation and use of the ASCIR. It ensures maintenance and development occurs with input from ASCIR stakeholders, fosters collaboration between the RCIS/NISU and spinal unit Directors and research staff, and assists the person with the role of AIHW Data Custodian to fulfil the requirements of that role.

NISU, a Collaborating Unit of AIHW, is responsible for the security, proper operation and use of ASCIR data. The AIHW Data Custodian at NISU (Dr James Harrison, Director) is responsible to the AIHW for ensuring that the operation of the Register and use of Register data comply with AIHW policies and procedures. The Data Custodian also ensures that the analysis and dissemination of the data are in accord with purposes approved by the AIHW Ethics Committee as well as security provisions required by Section 29 of the *Australian Institute of Health and Welfare Act 1987*.

Two groups of patients are admitted to spinal units: new incident cases and prevalent cases. From July 1, 1995 all new incident SCI cases were registered at the 6 spinal units by registrars, ward clerks, or other attending health care workers.

The registration process begins in the spinal unit after patient stabilisation. The Director at each participating Unit is responsible for data collection and patient consent arrangements in their Unit. Consent arrangements differ between Units.

During the acute phase, the first page of the case registration form is completed, a copy sent to NISU and the original filed in the patient's case notes. Upon arrival at NISU, the data are checked for completeness and transcribed into the ASCIR database. In the case of electronic data reporting, the data is entered using a data uploading program in the Register's software. This process is the beginning of case registration of new incident SCI cases.

In terms of data reported, the scope of the first form includes patient history, demographic information, clinical assessment of patients during their acute stage of SCI, and a description of the event that led to their SCI.

At discharge of the patient, the second part of the case registration form is completed. This form records details of their clinical status at discharge and complications during the course of treatment and rehabilitation. A copy is forwarded to NISU to complete the registration process and the original is filed in the patient's case notes.

In order for the ASCIR to capture other non-registered prevalent cases, the registration status of each case is assessed as patients are admitted to the spinal unit. If patients were not incident SCI cases and had not been registered previously, case registration forms are completed for each patient using incident SCI admission details from their case notes for the acute admission and rehabilitation phase of their episode of care. A readmission form is also completed for their current admission. In this way, the coverage of the Register is improved over time.

A readmission form is also completed for the majority of readmitted cases that were already registered to record current medical problems and outcomes for patients with medical problems serious enough to require specialised treatment in spinal units.

Data issues

Scope of SCI case registration data

All consenting incident SCI cases admitted to all 6 spinal units are reported to NISU for case registration. Complete enumeration of cases is confirmed by unit Directors or staff at the end of each reporting period (financial year 1 July through June 30). Ascertainment of traumatic SCI cases is high and these cases are the focus of the report. Paediatric cases (cases less than 15 years of age) are not currently included in the participating spinal units due to poor coverage of this group since child cases of SCI are usually treated in paediatric hospitals. Case registration of SCI from non-traumatic causes is known to be incomplete. These cases are often treated in other hospitals' specialised units (e.g. oncology) rather than at spinal units. These cases are briefly described in this report.

Rates

Incidence rates have been calculated as cases per million of the usually resident population of Australia. Population data were obtained from the Australian Institute of Health and Welfare and are similar to data presented in the Demographic Statistics Catalogue No. 3101.0 (Australian Bureau of Statistics). Annual rates were calculated using finalised population estimates as at 31 December for each year

Except where otherwise stated, all-ages rates have been adjusted to overcome the effects of differences in the proportions of people at different ages (and different injury risks) in the populations that are compared. Direct standardisation was employed, taking the Australian population in 2001 as the standard.

Confidence intervals

The ASCIR is designed to register all cases of SCI at ages 15 years and older, so sampling errors do not apply to these data. However, the time periods used to group

the cases (i.e. financial years) are arbitrary. Use of another period (e.g. January to December) would result in different rates.

Where case numbers are small, the effect of chance variation on rates can be large. Confidence intervals (95%, based on a Poisson assumption about the number of cases in a time period) have been placed around rates as a guide to the size of this variation. Chance variation alone would be expected to lead to a rate outside the interval only once out of 20 occasions. An extreme rate in a single period of enumeration should not be ignored simply because of a wide confidence interval—a time series may show such a rate to be part of a trend.

Trend analysis of external causes of SCI

Case selection of persisting SCI due to falls and motor vehicle related injuries was based on ASCIR records coded to the NISU's National Data Standards for Injury Surveillance (NDS-IS). Motor vehicle related SCI cases selected include cases who were injured during traffic and non-traffic accidents.

Annual incidence of SCI during financial years 1995–96 to 2003–04 (inclusive) was estimated using a Poisson regression model. The predicted count of SCI cases for a given financial year was divided by the Australian population data for that financial year to give an incidence rate per million person years at risk. Goodness-of-fit statistics were used to test for overdispersion. If overdispersion was found, the Negative Binomial Distribution model was used instead of the Poisson regression model.

To estimate age-specific trends, numbers of incident cases were modelled as a function of financial year with populations as an offset. The basic Poisson regression, model was $\log(\text{rate}) = \beta_o + \beta_1$ (financial year-1995–96), so β_o is the log of the baseline incidence rate in the first financial year (1995–96). The annual percentage change in incidence rate was obtained from the fitted model as $\exp(\beta_1)-1$. The level of $p \leq 0.05$ was taken to represent statistical significance. Analyses were performed using Stata statistical software (Version 8).

The goodness-of-fit test for the Poisson model using motor vehicle accident data (age group 15–34 years), motor cycle accident data (age groups 15–34 years and 15–85 years), all falls (high and low falls) data (age groups 15–85 years and 55–85 years), high falls data (age group 15–85 years) and low falls data (age groups 15–85 years and 55–85 years) indicated that variation in SCI counts were not significantly more than would be expected from a Poisson regression model (i.e. overdispersion was not occurring) and Poisson regression was used in the trend analysis of these data.

For motor vehicle accident data (age group 15–85 years) and high falls data (age group 55–85 years), the goodness-of-fit test for the Poisson model indicated that variation in SCI counts were significantly more than would be expected from a Poisson regression model (i.e. overdispersion) and the Negative Binomial Distribution regression was used resulting in higher p-values and wider confidence intervals in the trend analysis of these data.

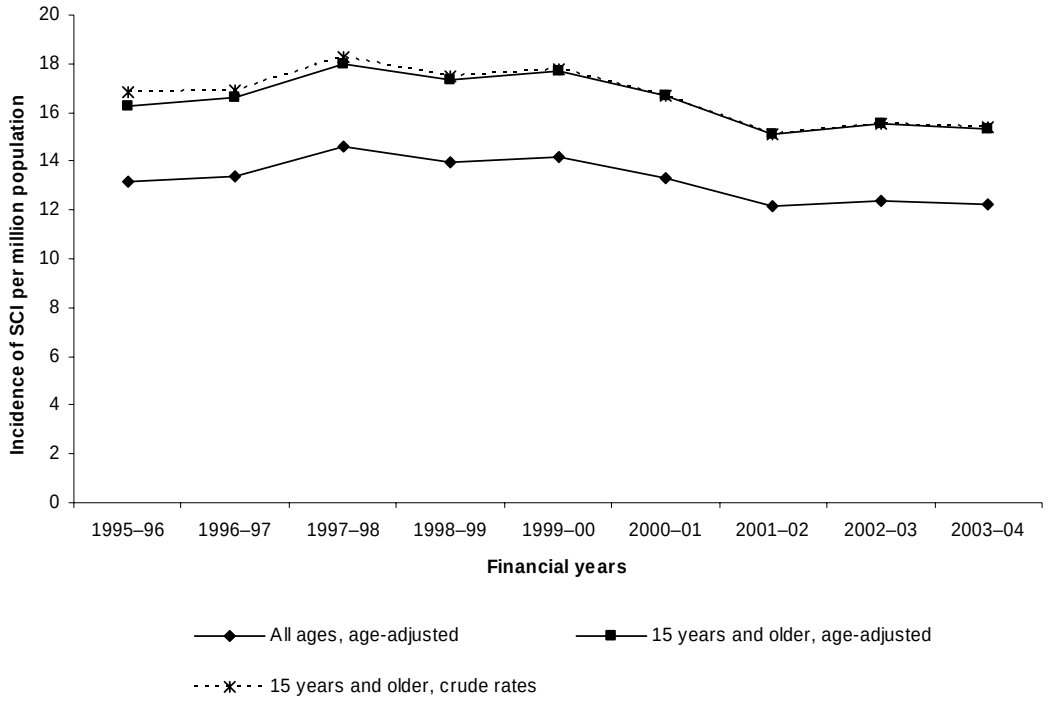

Figure A1.1: Incidence of SCI from traumatic causes by financial year; Australia

In this report, trends in the incidence of persisting SCI due to traumatic causes are presented in two ways. Both differ from the approach used in previous reports. This section describes how the methods differ and compares the values obtained from each (Figure A1.1).

Figure 3.1 presents annual rates, age-adjusted by the direct method to the Australian population in 2001. Age-adjustment was used to allow for effects of change in the age-composition of the Australian population. Analysis was restricted to ages 15 and older because that is the age-range for which ASCIR is considered to have good case ascertainment. These values are shown in Figure A1.1 as the series labelled '15 years and older, age-adjusted'.

Figure 5.1 presents results of Poisson modelling of rates. The modelled trend lines and the 'observed' values shown in Figure 5.1 (and the other figures in Chapter 5) are based on annual age-specific rates, which do not take account of changing age composition. Analysis was restricted to ages 15 and older, for the reason given above. Annual age-specific rates are shown in Figure A1.1 as the series '15 years and older, crude rates'.

The pattern of differences between the crude and adjusted rates follows from two factors: (1) rates of SCI are highest in early adulthood; (2) the proportion of the Australian population that is in this age group has declined.

In previous reports, we have generally reported all-ages rates of SCI, adjusted by the direct method. Rates calculated in this way are shown in Figure A1.1 as the series 'All-ages, age-adjusted'. This method does not allow for the likely under-ascertainment by

the ASCIR of traumatic SCI cases at ages less than about 15 years. The values resulting from use of this method are about 20% lower than rates for ages 15 years and older.

True rates of traumatic SCI in childhood are probably lower than rates in early adulthood. Hence, a version of the 'All-ages age-adjusted' series based on completely ascertained SCI at all ages would probably be higher than series 'All-ages age-adjusted' as shown in Figure A1.1 and lower than the series '15 years and older, age-adjusted'.

INJURY RESEARCH & STATISTICS

Spinal cord injury (SCI) is uncommon, but personal and health system costs per case are high.

This report presents information from the Australian Spinal Cord Injury Register (ASCIR) on new persisting SCI cases in the year 2003–04. During the year, 247 new cases of SCI from traumatic causes were registered in Australia, 82% of cases involving males. The most common clinical outcome of persisting SCI was incomplete tetraplegia (101 cases). The average duration of initial care of patients with incomplete tetraplegia was 116 days.

41% of cases were related to land transport, and 10% to water-related activities. Cases also occurred during sport and work. Falls caused 34% of persisting SCI cases, about two-thirds of these were falls from a height of 1 metre or higher, largely involving males aged 15 to 64 years, and commonly occurring during paid or unpaid work.

The ASCIR is a collaborative activity of the AIHW National Injury Surveillance Unit and all of the specialist spinal units in Australia.

ISBN 1 74024 521 0