A Review of the Needs and Opportunities for the Surveillance of Spinal Cord Injury

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Title:
A Review of the Needs and Opportunities for the Surveillance of Spinal Cord Injury

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Abstract:

In 1991, a national system of spinal cord injury registration that was initiated and developed in 1986 by Mr John Walsh (an actuary) came to an end. The National Injury Surveillance Unit (NISU) recognising that some level of national reporting should exist, sponsored a review of the support and opportunities for a national system of SCI surveillance.

It was anticipated that information obtained through the system would enable four aims to be met: the prevention of SCI by collecting information on its causes to enable changes to be made to reduce or remove risks; monitoring and evaluation of acute care and rehabilitation services; measurement of the long-term outcomes of SCI; and assessment of the needs of people with SCI.

The most important part of the review was an assessment of the needs for information on SCI, and identification of how they may best be satisfied. Through a consultative process, structured by the use of a protocol of standard questions, the views of spinal unit directors were sought as well as those from disability support and advocacy groups, rehabilitative interests, insurance, health department and research groups, and people directly interested in spinal injury surveillance.

In the review, five general questions were addressed and form the basis of this report:

1. What are the objectives of spinal cord injury surveillance?
2. How may surveillance of SCI be conducted to meet these objectives?
3. What is an acceptable way of meeting the needs of SUs?
4. What is an acceptable way of meeting the need for injury surveillance?
5. How should SCI surveillance work?

A Review of the Needs and Opportunities for the Surveillance of Spinal Cord Injury

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Executive summary

Beginning in 1986, data on spinal cord injury was collected by spinal units in New South Wales and registered using a system devised by Mr. John Walsh an actuary. It later developed into a national register and continued to operate until the end of 1991.

After the support of major funders concluded at the end of 1991, the National Injury Surveillance Unit (NISU) commissioned a study to investigate the demand for information on Spinal Cord Injury (SCI) occurrence and ways in which it could be satisfied.

As the principal mode of inquiry, interviews were carried out with a range of data users and unanimous support for a system of State and National surveillance was found. There was wide agreement on methods to be used for data collection.

This report makes the following recommendations.

- That a register of incident cases be established, and that a uniform core surveillance data set be agreed upon by spinal unit directors.
- That collection and entry of core data items be incorporated into the routine registration of cases by spinal units. The potential for obtaining some of these data directly from other hospital information systems should be investigated by spinal unit directors.
- That NISU manage a central collection of core data, with appropriate safeguards.
- That NISU further prepare regular statistical summaries from a national perspective and to provide an ad hoc information service. Depending on the level of work involved a source of designated on-going funding may be necessary.

In order for these recommendations to be implemented the report further recommends that:

- The need for special software to enable reporting within spinal units and to NISU be considered with regard to specific functions required, and funding to specify and develop this software should be sought.
- The form and content of feedback and reports to be provided by NISU be considered in detail in consultation with spinal units.
- A paper system of registration of incident cases be introduced as soon as possible to recommence registration, pending development of a computerised system.

Available evidence suggests that the population of people with spinal injury is ageing rapidly, and may thus be developing special needs for support and treatment. It is recommended that a register of prevalent cases be established to investigate and monitor the needs of this group. Steps to be taken in order to develop this are:

1. Establish a baseline register utilising existing SCI incident cases on the SCI register (once it is developed) and those cases of SCI readmitted to hospital and identified as unregistered SCIs.

2. Monitor incident cases through the incidence register.

3. Monitor deaths through the use of National Death Index

Author's acknowledgments

Much of this report derives from the expertise of those interested in the occurrence and sequelae of spinal cord injury. I would therefore like to thank the directors of the six Australian spinal units and other individuals who have participated in the review. Particularly, I appreciate the advice of Mr J Walsh, who already has contributed much to the understanding of spinal cord injury epidemiology in Australia.

A number of people have provided helpful advice on the production of this report. I would like especially to thank Dr J Harrison, Dr S. Quine and Dr D. Lyle for their supervision and comments on the planning and writing of this report. I am grateful to the National Injury Surveillance Unit for the financial support that enabled this work to be carried out, and the Department of Public Health for their administrative support.

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Contents

List of abbreviations

ABS	Australian Bureau of Statistics
AIHW	Australian Institute of Health and Welfare
ARIPD	Actuarial Research into Physical Disability
CRS	Commonwealth Rehabilitation Service
IMSOP	International Medical Society of Paraplegia
ISC	Inpatient Statistics Collection
MAA	Motor Accidents Authority, the agency that in New South Wales coordinates the compulsory third party insurance system
NHDD	National Health Data Dictionary
NISU	National Injury Surveillance Unit
NMDS-IS	National Minimum Data set – Injury Surveillance
QuadCare	The organisation, based in Hunter's Hill Sydney, under which the Walsh registration system operated and the annual ARIPD reports were produced
register	A data file of all cases of a health event that can be related to a source population
registry	The organisational activity concerned with maintaining a register of cases. Often it is associated with an institution that has an interest in conducting research; some would hold that in order to conduct research such a registry is necessary
SCI	Spinal cord injury

SU	Spinal unit. There are six of these in Australia, and together they are responsible for the acute care of nearly all cases of spinal cord injury
surveillance	The routine and systematic collection, analysis and interpretation of health data, used in the description and monitoring of a health event.

1 Introduction

Reasons for review

In 1986 a national system of registration commenced collecting wide-ranging data on all cases of spinal cord injury (SCI) admitted to the six spinal units (SUs) in Australia. The system was initiated and developed by Mr John Walsh, an actuary, and throughout the report this system of registration is referred to as the Walsh system.

It was anticipated that information obtained through the system would enable four aims to be met: the prevention of SCI by collecting information on its causes to enable changes to be made to reduce or remove risks; monitoring and evaluation of acute care and rehabilitation services; measurement of the long-term outcomes of SCI; and assessment of the needs of people with SCI.

The Walsh system of registration was supported by several funding sources, including the New South Wales Motor Accident Authority, the Disability Services Branch of the Department of Health, Housing and Community Services, and the Australian Institute of Health and Welfare (AIHW).

At the end of 1991 support by the major funders concluded, and was not renewed. Recognising that some level of national reporting should exist and that continuity of registration was important, the National Injury Surveillance Unit (NISU) supported in 1992 a reduced level of reporting. NISU, a part of the AIHW, had as its other aim a review of the support and opportunities for a national system of SCI surveillance. It is this review that is the subject of this report.

Objectives of review

The most important part of this review was an assessment of the needs for information on SCI, and identification of how they may best be satisfied. Consultation was held with as wide a spectrum of users as possible, but with a central emphasis being given to SUs. Views were also sought from disability support and advocacy groups, rehabilitative interests, insurance, health department and research groups, and people directly interested in spinal injury surveillance. Contributors to the review are shown in Appendix I.

It is recognised that many parties have an interest in surveillance data. Consultation was necessarily limited by time constraints, but it is believed that the views of a broad cross-section of interests, as well as the most important participants in spinal injury treatment, welfare and prevention, have been obtained.

Consultation meetings were structured by the use of a protocol of standard questions (Appendix II), and usually lasted between one and two hours. The questions related to the perceived value of information on SCI, and what the aims of surveillance should be;

strengths and weaknesses of the previous registration system; and views on future needs for information and ways in which they may be satisfied.

In the review five general questions were to be addressed:

1. **What are the objectives of spinal cord injury surveillance?** Why should surveillance of SCI be conducted? Who are the potential and actual users of surveillance data, and what are their specific information needs? Consideration of SCI as a public health problem also has a bearing on this question.

2. **How may surveillance of SCI be conducted to meet these objectives?** One approach to surveillance is exemplified by the previous system of registration, however surveillance may be carried out in a number of ways. There are strengths and weaknesses to the various approaches and an evaluation of these will determine which is the best method for meeting the objectives of SCI surveillance.

3. **What is an acceptable way of meeting the needs of SUs?** What are the particular information requirements of SUs? Did the previous system of registration successfully meet these, or are there particular features SUs would like to see in a new system? Could this meet the needs of other users?

4. **What is an acceptable way of meeting the need for injury surveillance?** Will a SU based register enable the objectives of surveillance to be met as well? Can the differing interests of SUs and those concerned with SCI surveillance be reconciled?

5. **How should SCI surveillance work?** After analysing answers to the above questions will it be possible to describe with some level of detail a future system of surveillance that may be implemented?

Answers to these questions were sought through meetings with directors and senior staff of SUs, previous funders of the system, the developer of the previous registration system, disability support and advocacy groups, and health and research department officials.

The literature on surveillance of spinal injury and methods of surveillance was reviewed to determine how SCI surveillance is being implemented elsewhere.

Methods

In 1992 NISU, having identified the need for a review, was able to fund its implementation. A project team (Dr J. Harrison, NISU; Dr D. Lyle, NSW Health Dept; Dr S. Quine, Dept of Public Health, Sydney University) was established, and in late 1992 a Project Officer (Mr C. Blumer) was recruited.

To identify the questions to be addressed in the consultation process, a protocol was developed. The principal aim of the protocol was to determine whether this system had met the interviewees' needs for information on SCI. It took as its starting point a review of the present (Walsh) system. This was framed within discussions about the system's objectives, utility, and operation, and how the respondents believed a future system of surveillance could build on it. In addition to local needs for information, the value of national reporting of SCI was also discussed.

Interviews were carried out during the first half of 1993. Preliminary findings and recommendations were presented for comment at a national meeting of SU directors in late June, 1993.

Outline of report

- **Spinal cord injury: the problem**

  Considers SCI as a public health problem which, although rare, has a high economic and social cost and its prevention therefore should be a high priority. The central role of SUs in the treatment of SCI in Australia is described, underlining both the implications for surveillance and the importance of obtaining their views about surveillance.

- **Surveillance: objectives and methods**

  Deals with definitions of surveillance and registration. The application of surveillance to SCI is considered, and methods of monitoring its occurrence explored. The value of a register-based surveillance system is considered.

- **Previous approaches to SCI registration in Australia**

  Describes the first attempts towards establishing national reporting of SCI, and the evolution, through the Menzies Foundation symposia, towards the registration system developed by Walsh.

- **The need for information on SCI**

  Synthesises the results of the consultation process. The conceptualisation of a ‘service configuration’, which illustrates where and how a person with SCI may be ‘captured’ by some system of surveillance is followed by a discussion of the aims proposed by the interviewees, which determine how surveillance should operate within this configuration. The desired objectives are discussed under four headings: Service planning and evaluation; Epidemiology; SCI prevention; and External demands for information.

- **Development of a new system for SCI surveillance**

  Suggests a surveillance system that reflects the views of, and feed-back obtained from, the interviewees. Based upon the registration of cases admitted to SUs, the system is viewed within the larger context of the total occurrence of SCI.

2 Spinal cord injury: the problem

Economic and social costs of SCI

Spinal cord injury is a significant public health problem. The consequences of injury may be divided into economic and social costs, both of which are substantial. Information from 1988 suggests between 300 and 400 new cases of SCI annually are added to an extant population of about 6000 (Walsh, 1988).[1] Surveillance data for the years 1986 to 1991 confirm this estimate - the annual number of traumatic cases of SCI admitted to SUs are shown in Table 1.

Table 1: Annual incidence of new cases of traumatic SCI admitted to spinal units in Australia

Year	Traumatic SCI cases admitted	Percent of total admissions to SUs (%)
1986	348	86
1987	326	84
1988	335	83
1989	341	82
1990	323	77
1991	268	77

Source: QuadCare, 1992[2]

The economic costs to society of this population may be divided into initial costs (for example, hospitalisation, rehabilitation, home modifications) and ongoing costs (for example, income support, ongoing medical/surgical, equipment, attendant care).

After estimating the populations of people with paraplegia and quadriplegia, Walsh constructed two models with different incident rates in order to project future monetary costs. In 1987, the annual low and high forecast costs were 156 million and 185 million dollars; for the year 2006 these increased to 188 million and 287 million per annum. (See Table 2.)

As the population of people with spinal cord injury increases, because their life expectancy now approaches that of the population at large[3], the ratio of ongoing to initial costs is expected to rise. The costs *per* patient will also rise as the cohort ages, and the total costs will thus be further multiplied.

Table 2: Estimated annual costs of spinal injury in Australia

Year	Model 1[+] Expected prevalence	Total cost ($million)	Model 2[++] Expected prevalence	Total cost ($million)
1987	6200	156	6400	185
1991	6594	164	7520	209
1996	7044	174	8841	238
2006	7647	188	11051	287

\+ Model 1: Rate of occurrence: 200 new cases per year.
++ Model 2: Rate of occurrence: 400 new cases per year.
Source: Walsh, 1988[1].

If the incidence of new spinal cord injuries were to be substantially reduced over the next few years, the total costs associated with the ongoing long-term care of the population already injured would not be significantly reduced for many years to come. Walsh[1] estimates initial treatment costs for both quadriplegics and paraplegics at the age of twenty years to be a little over 20% of the total costs they will incur during their lifetime.

A survey by the Australian Quadriplegic Association[4] also found that out-of-pocket expenses faced by people with severe disabilities were substantial. Conservative estimates put these at between $2800 and $7500 annually.

As SCI commonly affects young people, the personal and social costs of the condition are particularly devastating. Although some people with SCI live full and independent lives, the reality is that many require ongoing support, which often is provided by family members[5].

Prevention

Given the social and economic costs described above, the need for prevention of SCI assumes a high priority. Prevention may be either primary - stopping the injury from occurring at all, or tertiary - the prevention of complications and morbidity associated with the injury.

While the general causes of SCI and its complications are well documented, the continuing occurrence of several hundred new cases each year and the fact that 64% of admissions to spinal units are for the treatment of complications, indicate that further prevention is not easily achieved, and underscores the need for clear understanding of the environmental and social causes, in addition to personal factors, of SCI. [*]

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[*] Secondary prevention is taken to refer to shortening of disease duration or its amelioration through early detection. It finds little application to SCI therefore, but the potential of methyl prednisolone therapy immediately following trauma to the spinal cord presents a good example.

Payment of compensation and damages

Some people who sustain SCI receive compensation. The availability of compensation depends on the setting in which the injury was sustained, not on the resultant disability. Injury at work is often covered by workers' compensation. Road injury in some jurisdictions (notably Victoria) is covered by a 'no-fault' system of compensation. Some people who sustain SCI in other settings can take civil action in the courts against another party. If that party is found to be at fault, damages may be awarded. The level of compensation awarded in some cases has exceeded a million dollars. As stated earlier, expectation of life by people with SCI now approaches that of the population at large and such high rates of compensation may occur more frequently.

Rather than lump-sum payments, it has been suggested that structured settlements, which take into account initial costs (for example, home modifications) and annual ongoing costs (for example, income support, attendant care) should be used more widely.

Treatment of SCI in Australia

Spinal units in Australia are based on a model developed in Britain during the 1940s. Guttmann, at the Stoke Mandeville Hospital, established the principle that care of spinal cord injuries should occur within autonomous units, and that each patient should be attended by the same doctor and team from the earliest moment. The model is now used throughout the world, and in Australia the first spinal unit was established in Perth in 1954[6]. In Australia there are now six spinal units (Table 3) which provide the acute care for nearly all people sustaining injuries to their spinal cord.

The remit of SUs covers more than just traumatic SCI, and cases of non-traumatic SCI (for example, congenital conditions and spinal cord injury caused by neoplasms) are cared for as well. About 20% of admissions to SUs are for non-traumatic SCIs (Table 1).

Acute care of SCI requires months of hospitalisation, and many more months can be required for rehabilitation. In Australia rehabilitation may occur within the same hospital or at a separate rehabilitation centre. Because of the extended treatment time, close relations between people with spinal injuries and the staff of SUs usually develop. These often are maintained and strengthened by subsequent admissions for the treatment of complications.

Table 3: Spinal units in Australia

City	Unit	1993 size (beds)
Perth	Sir George Bedbrook Spinal Unit, Royal Perth (Rehabilitation) Hospital	40[a] 20 acute 20 re-admit
Adelaide	Spinal Injuries Rehabilitation Unit Royal Adelaide Hospital	40 10 acute 24 re-admit 6[b] nursing
Melbourne	Spinal Unit Austin Hospital	52 4–8[c] acute 24–28[c] re-admit 20 rehabilitation
Sydney	Spinal Unit Royal North Shore Hospital	30[d,e]
	Spinal Unit Prince Henry Hospital	32 7 acute 12[f] re-admit
	Moorong	2 re-admit 18 rehabilitation
Brisbane	Spinal Injuries Unit Royal Alexandria Hospital	40 6[g] acute –[h] re-admit 34 rehabilitation

a. The 40 beds are nominally divided 50:50; re-admissions are placed, depending on space, in either section.
b. The six beds may in the near future be used for re-admissions.
c. Thirty-two beds in total are divided between acute- and re-admissions.
d. In total, 29 beds are divided between acute, re-admission and rehabilitation cases.
e. An additional bed is occasionally used for short stays.
f. Normally ten beds are occupied by re-admissions.
g. One in five acute admissions spend some time in Princess Alexandra Hospital's ICU.
h. Re-admissions are also admitted to other wards of Princess Alexandra Hospital.

Phases in the occurrence of SCI

Four phases in the occurrence of SCI can be distinguished:

- an at risk situation occurs (pre-injury)
- an acute injury event happens, subjecting the spinal column and/or cord to high forces
- initial (or early) interruption to sensory or motor functions occurs
- function is not recovered, and permanent disability results.

These phases form a hierarchy. However, only some instances of the event at each phase lead on to subsequent phases (Figure 1). For example, many people who dive into shallow water (an at risk situation) are fortunate enough to avoid an acute injury event. Planning of any future surveillance system must take into account these phases.

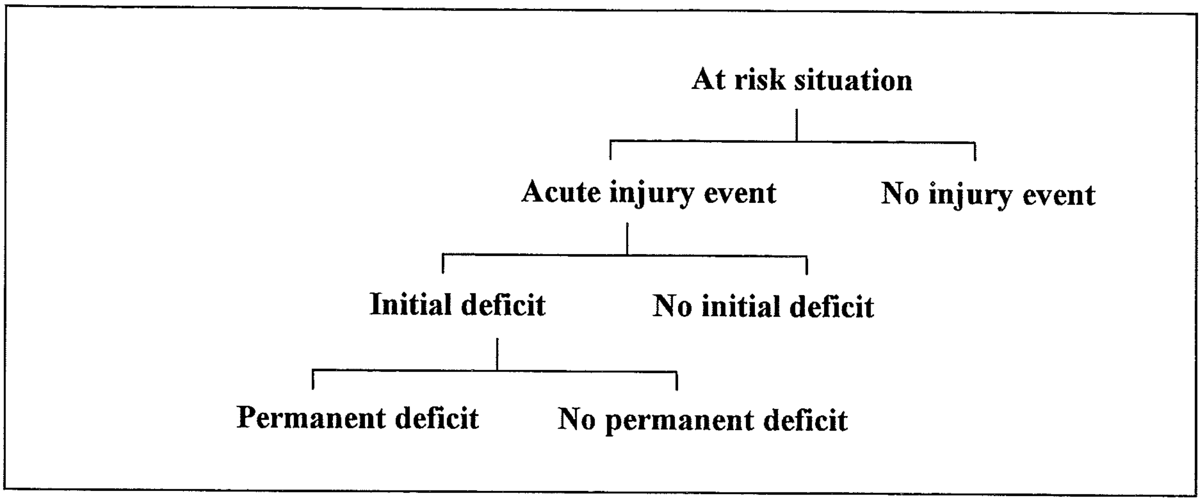


Figure 1: Phases in the occurrence of spinal cord injury

Conclusions

Spinal cord injury remains a major public health problem. In addition to the social costs incurred, particularly by younger members of society, the economic costs are also considerable and must be borne for many years. Both the primary prevention of SCI, and the prevention of morbidity associated with SCI, must therefore be a high priority.

The arrangements for the treatment of SCI in Australia, particularly its being based within six State-based SUs, facilitates the collection of information on the occurrence of SCI. Because of the size of the population, information may be obtained comprehensively for most cases of SCI, and therefore the population can be accurately described.

3 SCI surveillance: objectives and methods

Surveillance

Public health problems may be studied in a number of ways, one of which is surveillance. In contrast to surveys, which are of finite extent or duration, surveillance is an ongoing process which uses 'methods distinguished by their practicability, uniformity and, frequently, their rapidity, rather than by complete accuracy'. These are used in order 'to detect changes in trends or distribution in order to facilitate investigative or control measures'[7]. The scope of surveillance can also include the monitoring of mortality and morbidity, and the determinants of disease[8,9]. The setting of quantitative health targets has become popular in recent years in Australia, and monitoring progress towards them is an important task of surveillance systems.

There are three essential components to a surveillance system: data collection and collation, analysis and interpretation, and the reporting and dissemination of findings.

Data collection must be carried out systematically, and may take advantage of already existing data collections. Fundamental to any surveillance system is the use of a case definition, as it provides a criterion that may be used by all collectors to determine which cases should be included, and ensures that the same measure is being used both over time and by different collectors.

Analysis of surveillance data allows the pattern of disease occurrence to be described in terms of person, place and time, thus allowing comparisons across time or place, or between groups. It is these contrasts that provide insight into the causes of a disease or condition e.g. SCI and allows opportunities for its prevention or control to be identified. Those undertaking surveillance tend to acquire a familiarity with the condition under surveillance and with issues concerning its control. They are thus well placed to interpret surveillance findings to assist clinicians, policy makers, researchers and prevention personnel. Thus, an important part of surveillance is to suggest areas for more detailed investigation, and perhaps also to facilitate that process. Resulting from this, interventions may be designed and implemented. Surveillance can then also provide the opportunity for these to be critically evaluated.

Reporting can be divided into feedback to those collecting the data, and the wider dissemination of information to interested parties. Essential characteristics of a reporting system should be that reports appear regularly, that they are in a form that is readily understood and that reader's needs are addressed.

Surveillance should address public health problems which are of importance and which may be ameliorated through intervention. The form and aim of control measures should be based on (amongst other things) the information that surveillance data can provide. The intent of surveillance should be indicated by an explicit presentation of its objectives. Success is predicated on a clear outline being presented, and the simplest possible solution that can achieve the stated goals being realised.

Principles of a surveillance system

Design criteria

Simplicity of the system is an important feature. The data set should be straightforward, and there should be firm justification for the collection of each data item. How data are obtained and reported, and the configuration of the system ought also to be easily understood. The primary source of data are the Spinal Units with the acknowledgement that other sources of information exist. Rather than setting out to be all things, the system should be modest in its initial aims. After their achievement, additional studies may be based on it, and more elaborate investigations implemented, but enthusiasm for these should not be permitted to jeopardise the basic system.

Issues surrounding SCI are not static. The need to evaluate new treatments or other new needs for information arise from time to time, and it is important that a surveillance system be *flexible*, so that such issues can be responded to as they occur. A second aspect in which flexibility may be enhanced is in relation to other data sets. The use of *standard data definitions*, which enable SCI surveillance data to be linked to other data sets, allows a wider range of questions to be answered than would be possible if idiosyncratic definitions were used.

Timeliness is also an issue to be considered. If data are to be collected, it is important that it is of use to those collecting it. There should therefore be some feedback mechanism, which would operate within a time scale relevant to their needs. In the case of SUs this occurs at several levels. The first level concerns the need for day-to-day clinical information, which may be obtained directly from an SU-based register. The second level relates to annual or semi-annual summaries of clinical activity, and the third to trends in incidence and other characteristics of SCI from year to year.

Representativeness is a further attribute the surveillance system should possess - that is, information collected should be true of the SCI population generally. The previous system was not entirely representative, because only those cases passing through an SU were recorded. Recruitment of cases treated in paediatric wards, or general medical wards for elderly cases, would make the proposed surveillance system more representative.

The system must also be designed to ensure *propriety* in its operations. This term is used to encompass legal and ethical issues, with particular emphasis on privacy (*i.e.* meeting reasonable expectations to refrain from releasing or disseminating certain information), and on public duty (*i.e.* meeting reasonable expectations to release and disseminate information).

Considerations for SCI surveillance

Despite its fairly low incidence rate, SCI is a serious, chronic condition. It thus warrants attention. Information on causation as well as on the characteristics of the SCI population is necessary, so that appropriate interventions may be designed. As injury is the result not only of personal characteristics and behaviour, but also of social and environmental factors, the collection of detailed information on these other aspects is also required.

Because of the long treatment times required and the subsequent survival times of people with SCI, information on the prevalence of the condition should be obtained in order that hospital and community services may be planned accordingly. Quality of life, important enough as it is in itself, is also of interest because it reflects on community support, and because lack of well-being may point to future hospitalisation for complications that otherwise are preventable.

The extended periods of time required for the treatment and rehabilitation of people incurring injury to their spinal cord, together with the small number of institutions in Australia where treatment is provided, present good opportunities for surveillance of SCI.

A final consequence of the relatively low frequency and multi-causal nature of SCI is that changes in its incidence and patterns of causation may only be discernible over periods of years. If these changes are to be monitored effectively, a long-term view of surveillance must necessarily be adopted.

Possible methods of surveillance

Population surveys can measure the prevalence of SCI, but the information they can provide on incidence is minimal. Because of the low incidence rate of SCI a sufficiently powerful sample survey would be large and expensive to carry out. Surveys of members of advocacy or disability support groups offer more direct access to people with SCI, but their scope is limited by being representative only of those people who have joined the group. As surveys could not be repeated frequently, the information they provide on incidence and prevalence would quickly become dated, and changes in incidence or clusters of events could not easily be detected.

A periodic sampling of cases being treated within SUs would also be a way of gaining insight into the number of cases of SCI occurring, and their causes. Because case numbers are relatively small, each sample period would have to be quite long if enough cases are to be recorded to enable calculation of estimates having useful precision.

Hospital morbidity data are a potentially useful source of information on SCI, but at issue is the identification of acute admissions, as opposed to admissions due to complications, that is necessary in order to measure incidence. No certain distinction may be drawn on the basis of length of stay, and detailed information on the injury's occurrence (causation, time, date particularly) is unavailable through this method. It remains difficult to compile national hospital morbidity data, and routinely compiled data collections usually are not available until more than a year after the end of the year to which they refer.

A register is a collection of individuals possessing some well-defined condition, which may be used to evaluate treatments and monitor outcomes, and perhaps to register eligibility for treatment or services (an administrative use). There is also a connection between registration of events and the conduct of research into the specific condition being registered. Based on defined populations, an important aim for registers is that case ascertainment is as complete as possible. In the context of SCI in Australia, a collection of cases admitted to SUs may be regarded as a register. A collection that also includes cases not known to SUs would be a more complete register. The surveillance of SCI is a use to which such a register could be put.

In Australia a high rate of registration for SCI is theoretically possible. For cases that are treated within SUs this has been well demonstrated by the Walsh model which, however, did not address the registration of cases not treated in SUs. The value of surveillance based on a system of registration would be particularly enhanced if injury details for these cases were also obtained. Another advantage of registration is that surveillance of complications following initial treatment is also possible

Two categories of SCI cases could be registered, newly incident cases, and prevalent cases. A high proportion of newly incident cases could be registered by recording admissions to SUs. While some prevalent cases of SCI can be registered in this way, it is probable that a substantial proportion of people in this group are not admitted to a SU. Thus, if information about the population living with SCI is required, case recruitment beyond SU admission will be important. Fortunately, with survival times of many years, there will be repeated opportunities for recruitment of SCI cases to a register. This could occur during re-admission as well as through the efforts of support groups who have an interest in the welfare of people living with SCI.

4 Previous approaches to SCI registration in Australia

History

Prospective surveillance of spinal injury in Australia first occurred at the Austin Hospital, Melbourne, in 1978. An attempt to extend surveillance to other spinal units as a step towards national surveillance, was unsuccessful.

A second attempt at establishing national reporting of SCI was made during the early 1980s by John Walsh. As an actuary, Walsh recognised the need for good data for planning purposes. Beginning in 1986, a three year Commonwealth research grant enabled Walsh to develop a monitoring and reporting system. The system commenced operating in NSW, and evolved into a national register. The register had as its principal objective the evaluation of care received by people following their return to the community.

Sir George Bedbrook, deceased, former Emeritus Consultant Spinal Surgeon, Royal Perth (Rehabilitation) Hospital, approached the Menzies Foundation, inviting them to organise a meeting on the prevention of spinal cord injury[10]. As a result, two symposia were held, in 1987 and 1988. The first of these, *Towards Prevention of Spinal Injury*[11], reviewed what was then known about the occurrence of spinal injury in Australia; for example data collected by the Austin Hospital showed that the rates of spinal injury were high by world standards[12]. The primary recommendation to come from this meeting was that a registry of spinal injury should be established. At the second meeting, *Towards a Registry of Spinal Injury*[12,13], the aims of the proposed registry were defined. Amongst these were that a register of spinal injury would provide information on the incidence, causation, morbidity and mortality, outcomes and long term consequences of, and needs of people with SCI.

The meeting further recommended that the registry promote research into spinal injury, that prevention programs be developed, and that additional and more detailed data collections be undertaken. The final recommendations of the report were that a committee to plan and develop the registry be established, and that a core data set for the proposed register be defined.

The committee did not meet, and the recommendations were not implemented. The Commonwealth research grant was extended for a further year and, with subsequent support from the *Australian Institute of Health* and the insurance industry, the previous register initiated by Walsh continued operating.

At the end of 1991 the Motor Accidents Authority (MAA) of New South Wales (the major supporter) and the Disability Services Program of the (then) Commonwealth Department of Community Services and Health, declined to renew their funding of the project. Subsequently, the Walsh register operated at a minimal level, with records being kept only on the admission and discharge of patients from SUs for some periods.

Objectives

Walsh's original interest, which led to his developing the register, was in evaluating the quality and sufficiency of care received by people with SCI following their return to community living. He recognised that good data were essential for planning disability services, and his major objective therefore was to improve the scope of available data on the occurrence of SCI. Collection of accurate data on the incidence of spinal injuries through SUs was the first step towards this goal.

Case definition

The criterion for inclusion in the database was that a person be admitted to a participating SU. Admission practices and profiles (of traumatic *vs* non-traumatic for example) differ amongst SUs. Thus, while data are collected on whether the case was of traumatic or non-traumatic origin, there remains some doubt about the comparability of case ascertainment between SUs.

Structure

The operation of the Walsh system is described in Figure 2. During its period of operation, some 4300 incident cases of SCI were notified and over 7000 re-admissions recorded. Two instruments were used to collect data. The first related to book-keeping information, relevant to bed-usage in the spinal unit (the 'Short Form'). The longer second instrument, consisted of seven forms, and obtained data relating to the patient, demographic details, the cause of the injury, occurrence of complications and so on (the 'Long Form'). Copies of these instruments are attached, in Appendix V.

Data for the two instruments were obtained from case notes and through patient interview by SU staff or people who were employed by QuadCare for this purpose.

The book-keeping instrument consists of a monthly tally of admissions to and discharges from the SU, with details on whether the admissions were first or subsequent admissions, reason for admission, and an indication of the patient's neural deficit (none, para-or quadriplegia, complete or incomplete lesion) at discharge.

Summary statistics produced from this instrument are the number of admissions and discharges occurring during the month, and a list of in-patients. It is possible also to obtain from these data lengths-of-stay (LOS) data, for initial acute care and for readmissions for the treatment of complications.

The main data collection instrument gathered wide-ranging data on details of the accident causing the injury, clinical details at acute admission and re-admission, functional information at discharge and follow-up information. A brief summary of the forms that comprise the questionnaire is shown in Table 4.

Figure 2: Operation of the Walsh register

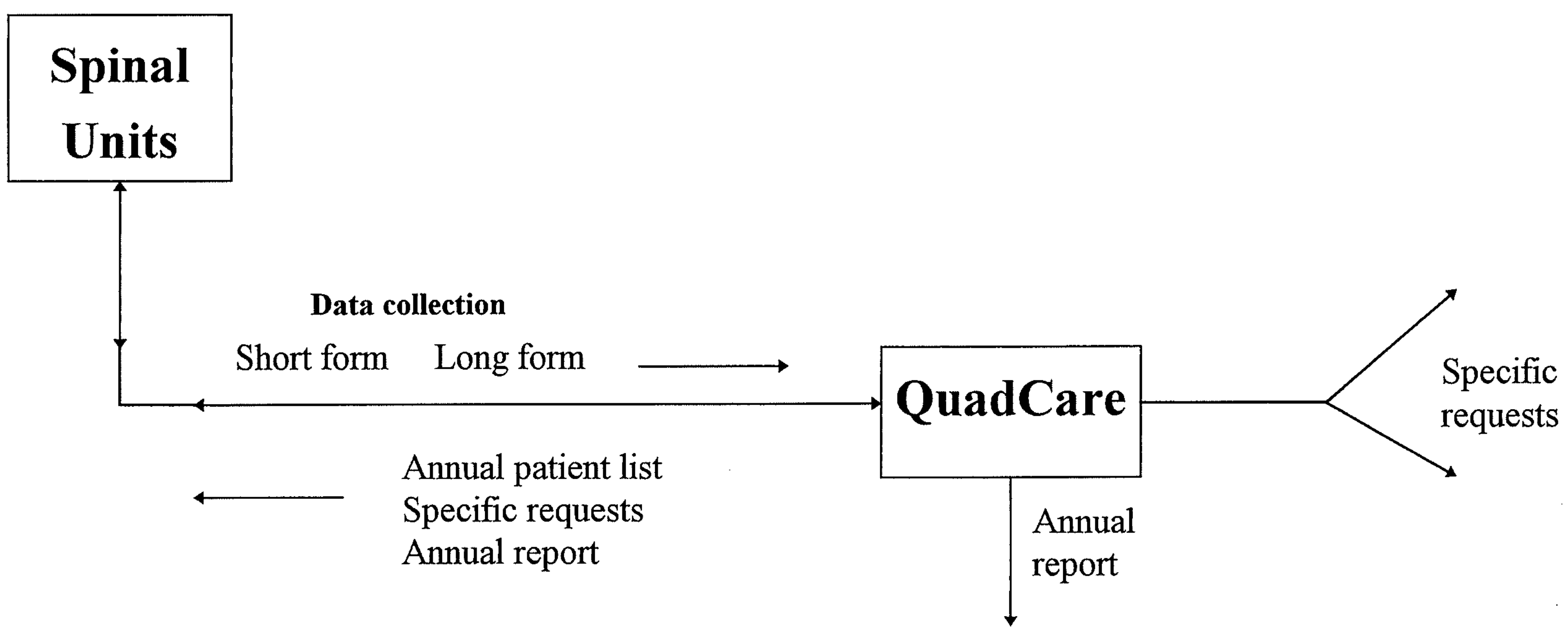


Table 4: Walsh Registration System: data collection forms

Form	Information collected on:	No. data items
Form A1	Identification, and pre-accident history	17
Form X1	Details of accident	9
Form A2	Initial clinical assessment	11
Form D2 (Acute)	Acute clinical discharge	7
Form D1	Basic discharge & follow-up information	17
Form R1	Re-admission details	8
Form D2 (Re-admit)	Re-admit clinical discharge	7
	Total items	**76**

Data from both the short and long instruments were entered onto the register each month at the State registry office, in Sydney.

The computerised central database application is written in APL (Version APL-Plus), a programming language designed for the manipulation and tabulation of data. Its use for medical data is unusual. The system was maintained on an IBM-compatible micro-computer. It has been necessary for all requests for information to be processed by Walsh.

Instructions have been written to guide data entry but there is little formal documentation to facilitate access to these data which requires a working knowledge of APL.

The most accessible form of information from the register is the series of reports published annually until 1993 by QuadCare.[2] These contain tabulations of age and gender, level of injury, whether complete or incomplete, and of traumatic or non-traumatic origin, and of primary traumatic causes (MVA, occupational, sporting). Additionally most reports had a theme, and additional tables are presented to illustrate these. For instance in the November 1989 report, transport and employment accidents were examined in more detail. Causes of readmission, categorised by State, and whether paraplegic or quadriplegic, were presented in the February 1989 report.

To provide feedback to the SUs, lists of patients known to have received treatment within SUs were produced each year.

A third way in which the database was used was in response to direct requests to QuadCare for specific tabulations of data. The provision of this information was dependent on its being extracted by Walsh.

The operating costs of this system amounted in 1989 to $110,000. Of this amount $34,400 were expended on data collection, and $40,000 on data analysis and administration of the registration system. (Note that data collection costs at one of the SUs were met locally.)

After the discontinuation of major funding in 1991, a small grant from NISU enabled data for the short form to be collected for a further year.

5 The need for information on SCI

Conceptual model

The 'service configuration', the pattern of services and needs a person with traumatic SCI encounters during his or her course of treatment and eventual re-integration into the community, may be used as a framework for a description of the information needs put forward by contributors. At each stage different institutions are involved, and a range of indicators are of interest to the various groups. The epidemiology of SCI and its complications, prevention of SCI, and satisfying external demands for information, are the primary objectives of a surveillance system for SCI.

An earlier representation of the objectives of surveillance, by the Menzies Foundation symposia, divided needs for information into short-term (causation, incidence: concerned with initial acute treatment and rehabilitation) and long-term (outcomes, needs: following an SCI person's re-integration into the community). An alternative rubric, based on types of function, distinguishes the planning and evaluation of SCI services, the epidemiology of SCI and its complications, prevention of SCI, and satisfaction of external demands for information, as the primary objectives of a surveillance system for SCI.

Implicit in the service configuration is the kinds of information which should be obtained and where and how surveillance may best be conducted. This, in turn, leads to a more informed plan for surveillance of SCI. Table 5 shows the five main areas in which care and prevention services are delivered, together with the kinds of indicators that are most informative at each stage.

Efforts directed to the prevention of SCI obviously occur prior to the occurrence of the injury. Following injury (to the right of the vertical dashed line) are acute retrieval, definitive care and initial rehabilitation, provided by SUs. These require in the order of six months. Rehabilitation is then conducted through centres for rehabilitation, some of which are integral to SUs. Re-integration of the spinal injured into the community can then occur either directly into the community or through a half-way house, such as Berala (a service provided by the NSW Paraquad Association). At each of these stages there are differing needs for information, and opportunities for its collection.

In order to best measure the incidence of SCI it is desirable that data collection for surveillance occurs soon after the injury event. If this is not done, cases may be lost through early mortality, or, in the longer term, through loss to follow-up once discharge to the community has occurred. Balanced against this is the need to consider the convenience of data collection, and the value of the information to those collecting it.

Table 5: The spinal cord injury service configuration.

Stage:	Primary prevention	Acute retrieval & initial care	Definitive care and initial rehabilitation	Rehabilitation & reintegration into community	Long-term welfare
Group:	Public Health/ Road Safety/ Occ. Health & Safety	Systems of care Ambulance services & paramedics	SUs Early rehab.	Rehab. centres Support groups	Support & advocacy groups Govt. agencies Insurance groups
Measures & Indicators:	Incidence Aetiology	Incidence Survival	Incidence & mortality Complication rates Lengths of stay (LOS) Financial status	Incidence Prevalence Indicators of functional independence	Prevalence QOL Welfare indicators Financial status

Objectives

Clear definition of the objectives of surveillance is essential for planning the details and operation of a future surveillance system. A major part of the consultation process therefore was aimed at reviewing the objectives of SCI surveillance, by evaluating those of the Walsh system, and by discussing possible future aims.

The purpose of SCI surveillance, as stated in the Menzies Foundation symposium report, was to collect information on the incidence, causation, morbidity and mortality, outcomes and long term consequences of, and needs of people with, spinal cord injury. Have these stated aims been addressed adequately, and are they still appropriate? Consultation with the various groups revealed a divergence of views although there was general agreement that the primary objectives, understanding causation and the measurement of incidence and morbidity, had been addressed fairly successfully, but that the aims of collecting data on outcomes and needs had been less successful. It seems that the precise purposes to which such information would be put have remained, in the main, unstated. Consequently, data on these matters in the Walsh system have been under-utilised, and this lack of use has hindered clarification, for potential users, of the ways in which such information could be used (*e.g.* in planning services).

The review provides an opportunity to reconsider the aims of surveillance. In addition to the planning of services, other purposes to which surveillance data may be put include description of SCI epidemiology, and satisfaction of a demand for information from outside the SCI service configuration.

Service planning and evaluation

The need to plan and evaluate services for people with SCI emerged as the most frequently stated objective. It is this aim that requires information on prevalence, incidence, types of morbidity, and service needs of people with SCI. Planning of services was referred to at two levels; within SUs, and within the community.

Within SUs services can be planned on short- and long-term bases. As an example of the first, the admission policy of a unit in regard to non-traumatic cases for example may be determined by the availability of vacant beds. Longer term planning concerns bed numbers and the balance of re-admissions to acute admissions. Relevant indicators are the prevalence of SCI, and complication rates in the population of SCI cases served by a unit. Most of the SUs directors said that about half of the beds in their units were occupied by cases re-admitted; usually for complications (Table 3). Although SCI incidence is felt to be decreasing, its prevalence is still increasing, and as the affected population ages, the occurrence of complications is expected to increase.

A particular example of service provision was provided by Dr S. Rutkowski (Royal North Shore SU). Interested in providing country clinics, she wished to use information on the number of people who might attend, in order to assess whether the clinics would be sufficiently used to warrant provision.

The planning of services was also referred to at the level of SUs. A specific example is the mooted establishment of a third SU in NSW at Newcastle. In judging the need for such a service, regional and State prevalence and incidence trend data is critical.

The need to plan services for people with SCI living in the community is the next area for which information is sought. Indeed, it was with this aim in sight that the Walsh system was originally established. Data from this system have been used by the Commonwealth Rehabilitation Service, the Australian Institute of Health and Welfare, and disability support groups (State and national) to determine levels of need and to justify various services for people with SCI. Requests for information received by Walsh are summarised in Appendix III. Examples of services include the provision of home care services in particular areas, bladder and bowel care equipment, and specialised nursing homes. As the population ages, the need for this latter service will increase further. Newly emerging groups, such as high-level quadriplegics, and spinal cord injured people with brain injuries also require specialised services. A pertinent observation by Mr N. Glass (Paraplegic & Quadriplegic Association of WA) was that, while the needs of people with SCI were well understood, the most urgent need was for local data so that appropriate services could be directed towards the areas of most need. Most of the support groups shared the observation that, with the increasing prevalence of people with SCI, the key emerging issue is the long-term welfare of these people.

The evaluation of SU and community services is another area for which information is sought. Spinal units are responsible for delivering high quality treatment to their patients and are accountable to the hospitals in which they are sited. At the administrative level there is the need to monitor the number of occupied beds in a ward, and the levels of injuries of the patients in those beds, in order that staffing levels may be determined or justified. The further introduction of case-mix (diagnosis-related groups) accountancy into hospitals further underlines the need for readily accessible patient-specific information. Data particularly valuable in this regard are again injury level, lengths of stay and complications treated. In the words of Mr J. Ker (Royal Perth (Rehab.) Hospital spinal unit, the need is for 'frequent clinical audits.' Most directors of SUs reported that preparation of annual reports, because of the need to compile patient information, was time-consuming; their production would benefit very much from the computerisation of this information.

The occurrence of complications can also be used as an indicator of the efficacy of various treatment and preventive regimes used by the different SUs. A case in point is the demonstration by the Prince Henry SU of the value of a more sensitive test for the diagnosis of thromboembolic disease (Engel et al[14]). As a result of using this test, the need for more widespread preventive action is suggested. Longer term outcomes, such as rates of complications following discharge from acute care, and rehabilitative outcomes as the technology becomes available to measure them should similarly be evaluated.

SUs represent a central agency responsible for the supply of medical services, the efficacy of which may be directly measured. However the provision of community services is by comparison diffuse, there being a number of agencies who supply a wide variety of services and equipment. There is little to ensure that people do not 'fall into the gaps' between agencies, and their long-term well-being cannot be assumed. The assessment of needs and service provision for the population living with SCI thus assumes a high priority.

Epidemiology

The epidemiology of SCI may be divided into two parts: that which is concerned with the occurrence of SCI; and that concerned with describing the morbidity experienced by people living with SCI.

Occurrence of SCI

Foremost in any discussion of SCI must be a consideration of the condition's incidence. In Australia data from the Walsh system suggests that the incidence of SCI is declining, there being presently about 300 cases *per annum* (Table 1). Evidence of a dramatic decline over the last few years[15] in the occurrence of motor vehicle accidents (MVAs), which cause half the cases of SCI, supports such a reduction. However there remains a need for the decrease in incidence to be confirmed.

In measuring incidence a weakness of the previous system was its reliance only on cases admitted to SUs, albeit an operational step easily implemented and one that obtained information on the cases of most interest to SUs. Although Walsh considered the number of paediatric and elderly cases treated outside SUs to be few (three to four childhood injuries annually), information, even if minimal, on these cases should be sought so that their rate of occurrence may be verified. A second group of unaccounted cases are those not surviving to be treated within SUs. Professor R. Jones (Prince Henry SU) observed that, prior to education of paramedics and the public, 30% of SCI cases died before being admitted to hospital. There is a lack of any data to indicate the current rate of pre-admission mortality, and therefore the total incidence of SCI.

Changes in aetiology provide a second argument for monitoring SCI incidence. In addition to the decline in motor vehicle accident-caused SCI, the occurrence across Australia in 1992 of a larger than usual number of cases in the elderly was mentioned by Dr R. Marshall (Royal Adelaide SU). Spatial variation, particularly between States, should also be monitored, according to Dr V. Hill (Princess Alexandra SU), so that the differing patterns of occurrence may be identified. For example more cases resulting from diving into shallow water are reported in Queensland than in other States. Identification of these patterns may be used to initiate more detailed investigation of their causes, and to develop locally relevant preventive strategies.

A trend referred to many times is the increasing survival of people who have sustained SCI. After incidence, therefore, case mortality is the next area in which information should be sought. There are three pertinent questions: How many deaths occur? When do they occur? How or why do they occur? Rather than seeking a numeric answer to the first (which of course must ultimately equal the number of incident cases), a more useful response might quantify rates of survival at different stages of a person's path through the service configuration. Of total deaths from SCI Selecki *et al*, in 1981, recorded a pre-hospitalisation death rate of 78% (22% died during initial hospitalisation)[16]. What is the rate now? The mortality rates following rehabilitation, at one or five years following re-integration into the community, are statistics that might also be sought. The second question–When do deaths occur?–is phrased so as to emphasise survival times. Several interviewees referred to the increased survival times of people with SCI, and John Walsh and Ms F. Purdy (Australian Quadriplegic Association) commented especially on the recent appearance of a cohort of high-level ventilator-dependent quadriplegics. Good data on their survival, and for people with SCI generally, is therefore of much interest. In addition to time of death, it was suggested that information on cause of death should be obtained. Indeed, an audit on causes of death in South Australia was cited as one of Dr Marshall's particular interests. With longer survival times, alterations in morbidity patterns are being observed - an increase in the occurrence of cardiovascular disease being one example. Will this change be associated with a different pattern of mortality, and will there be a need for a new strategy to prevent deaths from cardiovascular causes?

Taking into account the appearance (incidence) and disappearance (mortality) of cases of SCI, an issue that remains is the size of the pool - that is the prevalence of SCI, and whether it is increasing or decreasing. For service planners the prevalence of SCI is the most important indicator of the level of need for services. Reflecting this, most interviewees referred specifically to a need for data on numbers of people with SCI. Dr Hill commented that one of the principal benefits of the Walsh system has been its provision of prevalence data.

The size of the SCI population in Australia has been estimated by Walsh to have been about six thousand in the late 1980s.[1] While the incidence of SCI is declining, it is generally believed that the prevalence of SCI is increasing because of the large increases in survival that have occurred in recent decades. This demographic transition is leading, for the first time, to the existence of an older and aging SCI population. A second feature of note is the recent appearance of a cohort of ventilator-dependent quadriplegics, as mentioned above.

The conduct of a census of SCI cases in South Australia was mentioned by Dr Marshall as one of the projects that she would like to pursue, and a similar exercise at the national level would also seem worthwhile. It has been remarked by several respondents that this population size makes it a worthwhile study - it is small enough for there to be complete ascertainment of cases, but is yet large enough for meaningful conclusions to be drawn from a study. However, a census on prevalent cases could be difficult and expensive to conduct, especially locating cases that are not on the Walsh system which has names and addresses recorded.

Complications associated with SCI

The impact of the medical complications of SCI is a major issue. About one-half of all SU beds are occupied by people being re-admitted for complications. While the prevention and treatment of the 'traditional' complications (urinary tract infections, pressure sores &c.) have become routine, the profile and occurrence of complications is altering. As the SCI population ages and survival times further increase, new complications are appearing, for which standardised prevention and treatment practices have yet to be developed. One step towards this occurred during 1993 with the publication of a study conducted by the Prince Henry Hospital SU[14] on the detection of deep venous thrombosis, which emphasises the need for more widespread prophylaxis. Other complications that need to be better described, epidemiologically, include cardiovascular and lipid disease, haemorrhoids, arthritis, and chronic pain.

SCI Prevention

The first Menzies Foundation Symposium on SCI[11] had as its principal focus the prevention of SCI, and participants advocated the establishment of a registry so that research into the causation of SCI could be conducted towards that end.

Prevention of SCI remains a prime objective of the people consulted in the course of the review. The collection of causation data by the Walsh system was cited as one of the main benefits of the system. Dr Rutkowski noted that this was particularly because of its utility to the education program conducted by Dr J. Yeo (Moorong, Royal Rehabilitation Centre, Sydney). Dr Yeo suggested that investigation of the causes of SCI should remain the critical objective of surveillance. The availability of causal information in annual SU reports and for general education of the public was also much valued.

Dr Hill noted that the Walsh system has not been used to investigate in detail the ways in which car accidents cause SCI. That little had been contributed towards a detailed understanding of causation was echoed by Dr Harrison (NISU). He stated that the easily observed behaviours associated with SCI (diving into shallow water, for example) are now well established, but the identification of new associations has become more difficult. This is because groups of people involved are smaller, and the associations with SCI may be weaker. He sounded a note of caution, pointing out that surveillance systems tend not to be well suited to studying questions of causality, focused epidemiological studies often being necessary. The importance of establishing these associations however remains, and, according to Dr J. Ozanne-Smith (Monash University Accident Research Centre) is accentuated by the possibility that the observed cases of SCI may represent the tip of an iceberg, in the sense that these injuries can point towards the occurrence, through the same mechanisms, of many less severe injury outcomes.

External demands

In addition to the agencies directly concerned with the provision of medical and community support services, there exists a large range of other users seeking information on the occurrence of SCI. These may be described as external demands.

Notable among these is the insurance industry, through its role in the compensation of victims of motor vehicle and occupational accidents. With the increased life-expectancy of people with SCI, there has been a trend away from paying out lump-sum amounts, in favour of the provision of structured settlements. The availability of information on life-expectancy, together with knowledge of the expenses SCI-individuals face during their life, enables the industry to evaluate the provisions that need to be made for compensation payouts. Ms A. Deans (Motor Accidents Authority (MAA)) said that in addition to demographic indicators, information on the functional and social outcomes of people with SCI and their long-term care was also of interest.

Information on SCI was often sought from Walsh for education purposes. In addition to the use of material by SU directors for teaching purposes, information has also been frequently requested by research students doing projects on disability or rehabilitation. A further example provided by Walsh was the use of road trauma incidence rates for a public television awareness campaign in South Australia. There is also a need to inform patients and their families of the nature of SCI and also of the long-term morbidity and outcomes likely to be encountered.

As SCI is a 'high-profile' injury, enquiries from the media are often received by staff of SUs. Information on numbers of people with SCI and how frequently SCI occurs is sought. Other examples of requests for information over the past couple of years have been collated by Walsh, and are shown in Appendix III.

A use of surveillance data cited by Dr Hill, for which information on probable outcomes and life-expectancy is needed, is in the support of evidence of expert testimony in litigation. Information on probable outcomes and life-expectancy is needed for cases in which damages are being sought where there exists a need for some assessment to be made of the costs and outcomes that a person with SCI may probably expect to face during his or her life.

Dr Harrison recorded the interest of the National Injury Surveillance Unit (NISU) in information relating to the occurrence of SCI. The Australian Institute of Health and Welfare, the parent body of NISU, is the national health information agency. NISU has the responsibility for reporting on, and monitoring rates of, injury generally. Responding to external requests for information on all aspects of injury is an important part of its activities. The ability to provide such information on SCI, because of the injury's impact, represents therefore a part of its functions that it is clearly desirable to fill.

The publication during 1992 of the document 'Goals and Targets for Australia's Health in the Year 2000 and Beyond'[17] illustrates another area in which surveillance data can be used. Injury is one of the target areas selected for a reduction of its impact on health: although SCI is not specifically mentioned in the document, the settings for which reductions in incidence are sought—transport, industry and falls, particularly in the elderly—are also the primary causes of SCI. The rate of occurrence of SCI in each of these categories is therefore of interest. NISU has responsibility for monitoring progress towards achievement of the national injury targets.

Australian national statistics on SCI should be compatible with those reported internationally. Mr J. Ker (Royal Perth (Rehab) SU) identified the need to use consistent outcome statistics, so that the level of care in Australia and New Zealand for example could be compared with that provided elsewhere.

Research

Australian SUs have academic interests revolving around various aspects of SCI and the size of the Australian population offers an ideal opportunity for research into all aspects of care and the long-term outcomes of people with SCI. For example Dr Hill is interested in the detailed investigation of car accidents, and particularly those in which roll-overs occur[18]. Dr D. Brown (Austin SU) has published work on the psychosocial aspects of SCI[19,20,21,22]. Dr Rutkowski recorded that as well as being a source of cases, surveillance data were often also used as background information for research papers which may draw specific data from other sources.

The existence of a network of units with somewhat differing treatment regimes, in combination with a data system able to monitor outcomes, is seen as a valuable foundation for conducting research into a range of different therapies. The conduct of drug-trials particularly was cited in this context. Demonstrating the efficacy of methyl-prednisolone and developing a standard protocol for its use was the example most commonly cited, but the development and evaluation of long-term anti-coagulant therapy was also referred to by Dr Hill as an issue requiring resolution.

Moving from SUs to a consideration of longer-term outcomes, Walsh stated that his intent in establishing surveillance was to facilitate the conduct of research into the long-term well-being of people with SCI. For example, by obtaining information on employment or levels of independence the determinants of well-being in people with SCI may be explored, and their health and welfare thus better promoted. Dr Harrison noted that the Australian Institute of Health and Welfare has a Welfare Division to which these issues may be relevant.

A feature of the SCI community is the strength of its support and self-advocacy groups. While the needs of these groups for information have already been cited in the context of service development and planning, a more general use of the surveillance system should also be acknowledged. The information it provides should be regarded as a resource, to which the community has a claim. The direction and utility of the surveillance system should therefore take into account the views of the community, in order that it may develop positively and benefit further from the high level of support that already exists.

As a concluding note, Dr Yeo, among others, cautioned that the system of surveillance should not attempt to be all things to all people, and risk failing to achieve its primary purpose. It became apparent that the Walsh system, in attempting to address objectives across the service configuration, had become large and unwieldy. However an overriding comment was that surveillance had been initiated, and that the system's worth lay in this and the creation of a significant and useful body of data. The highest priority now is that a basic surveillance be re-established which, once accomplished, may facilitate any number of studies.

6 Development of a new system for SCI surveillance

Introduction

A new system for SCI surveillance must take account of the sites at which cases (and suspected cases) might be registered, and the flow of cases between them. Possible paths through the service configuration that a person with SCI may follow are outlined in Figure 3.

'New cases' entering the service configuration include cases of spinal cord damage, cases of spinal column damage putting the spinal cord at risk of injury, and cases where such damage is suspected.

Most 'new cases' are admitted to a spinal unit. Some cases are believed to be admitted to another clinical service. Some cases die soon after injury (from SCI or from other injuries), and these would normally be referred to a coroner.

Within clinical services, new cases are assessed to determine whether cord injury has occurred, and whether there is a risk of (further) cord injury. (A very important group includes cases where unstable spinal injury occurs with little or no cord damage.)

In some relatively minor cases, cord damage is transient. Otherwise it persists indefinitely. (On advice from spinal unit directors, 'persisting' cases are defined as those continuing for three months or longer.) New persisting cases are the main source of prevalent cases of SCI in Australia. (Presumably, a few cases may also arrive through immigration.) Prevalent cases may, from time to time, be re-admitted to a spinal unit, or to other clinical services. These people may also be members of SCI support or advocacy groups.

Death or emigration of people with SCI reduces the prevalent population.

The next two sections outline an approach to surveillance of incident and prevalent cases. The rest of the Chapter deals with the practicalities of implementation.

New cases

In Chapter 5, it was stated that collection of data on newly incident cases should occur as close to the time of occurrence of the injury event as practical, to minimise loss of cases due to early mortality and loss to follow up. The point at which injury cases are retrieved might thus be a good stage for data collection to begin. Information on patient condition, location of the event, and the circumstances of retrieval could be obtained directly-especially important for cases who do not survive to be admitted to one of the SUs. The chief difficulty with having registration on data collected during retrieval, is case identification. Some cases of SCI are evident at the time of retrieval, others are not. Most are among a larger group of cases who either are assessed as being at risk of SCI and transported accordingly, or some may not be recognised as being at risk of SCI at the time of retrieval. With diagnosis likely to be incomplete and imprecise at this stage, registration of SCI cases during retrieval is not feasible.

Registration of cases during admission and treatment in SUs provides a better base for surveillance. Most cases of SCI are treated, soon after occurrence, within one of only six SUs. The proximity of SUs to the occurrence of the injury, in temporal terms, ensures that information can be obtained relatively soon after the event. Because of their need to plan, to undertake research, and to justify their services, SUs have a strong motive for obtaining information relating to their patients.

Spinal units should be the principal site for SCI registration. However, it must be considered that there may be some cases of SCI, especially children and the elderly, that are not managed by SUs during the acute phase. In addition, some cases of people with SCI may die prior to admission to SUs. SU registration alone, therefore, would not provide complete coverage of incident SCI cases. Other methods would be required to identify and register these cases if comprehensive full registration of SCI is to be achieved.

Registration of all new admissions to a Spinal Unit is the key part of the system. Unit Directors have indicated their willingness to participate, and have endorsed a surveillance data set (Appendix IV). Surveillance data set information should preferably be recorded on a form that also serves other SU purposes (e.g. as a case cover sheet). The form may be on paper or electronic.

Registration of those cases not admitted to a Spinal Unit should be encouraged. Clinicians and facilities known to care for such cases should be advised of the register, provided with paper forms, and encouraged to complete them. Estimates of under-enumeration will be made periodically by analysis of morbidity data collections.

Registration of early SCI deaths should be attempted. Primary sources of information on SCI deaths are forensic pathologists attached to coroners' offices. It may become possible to identify these cases from a computerised coroner information system, though this is not yet in place.

Most of the same data items are relevant to early deaths, but several are not. The data set for SCI early death needs to be specified (probably as a sub-set of the standard one).

Prevalent cases

The foremost features of the SCI population in Australia are that it is increasing in size, and that it is aging (see Chapter 2). The impact of this population on health services is substantial—presently half the beds in SUs are occupied by cases re-admitted for the treatment of complications. As well as increasing in numbers, with an aging population, the use of health services will further increase. In particular, increased numbers of hospital beds will be required for the treatment of increased rates of morbidity; more community carers, who can contribute to the prevention of sickness requiring re-hospitalisation, will be required; and more specialised nursing care will also become necessary. The prevalence of SCI should be established so that the best possible planning of future services may occur.

Of particular interest are people who were not registered to the Walsh register. The presumption is that their lack of contact with SUs (they would otherwise have been registered) indicates relatively good health. This group, too, is likely to be ageing, and the level of burden they will place on SU support and clinical services should be evaluated. It is suggested therefore that all people with traumatic SCI be registered in a SCI Prevalence Register, so that the prevalence of SCI can be measured and the increasing health care demands and requirements of the SCI population may be monitored. A register may be kept up-to-date by monitoring SCI incidence and mortality.

Surveillance of SCI prevalence presents two problems: estimating the prevalent population at some point in time, and monitoring additions to, and subtractions from, this population.

Initial estimation of the prevalent population can be based on several measures, each of which is incomplete. The starting point should be the register of about 4300 cases collected by the Walsh system in Spinal Units since 1986. Best estimates suggest that this is about half the number of prevalent cases. Ascertainment may be increased by one or more of several methods: advertised invitations to join the register; collaboration with SCI support and advocacy groups to make use of membership lists; and inspection of pre-1986 records of Spinal Units. It may be possible to use findings from two or more partial sources to estimate the total population size.

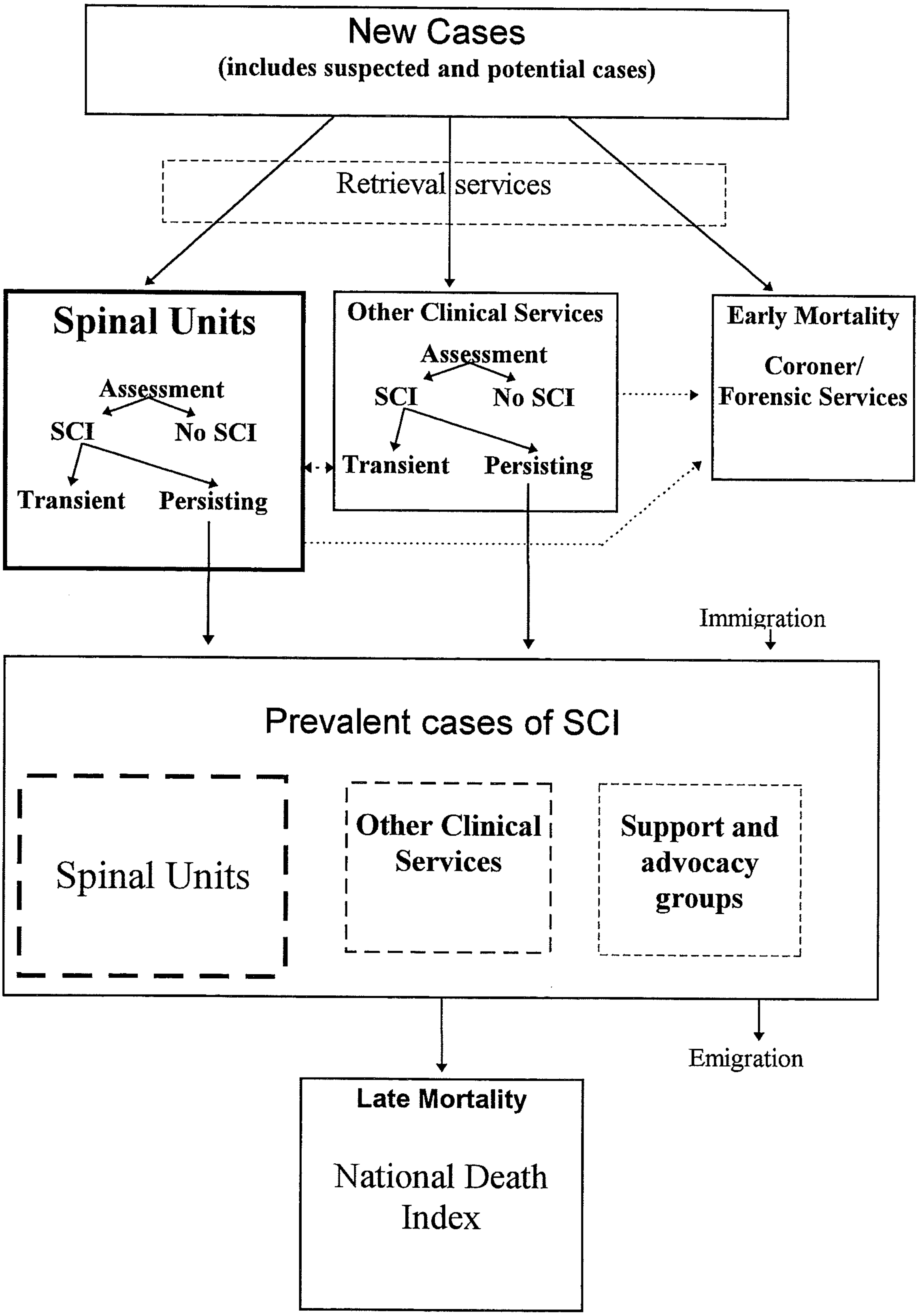
Monitoring of change in the prevalent population depends largely on two sources of information. Most additions to the population are new cases which should be registered in the SCI Incidence Register outlined above. Not all incident SCI persists long enough to warrant inclusion in a register of prevalent SCI. For practical purposes, a definition of 'persisting' new cases of SCI is required. Cases in the incidence register which meet this definition should be added to the register of prevalent SCI cases. As mentioned above, spinal unit directors have suggested a duration of three months from the date of injury as a reasonable indicator of persisting cases.

Most subtractions from the prevalent SCI population result from death. The newly developed AIHW National Death Index provides a means for monitoring deaths. The Index can be used (under certain conditions) to check whether individuals, known by name, have been entered onto an Australian deaths register.

Immigration and emigration probably account for a small proportion of change in the prevalent SCI population. At present, it is not suggested that special efforts should be made to measures this.

Recovery from 'persisting SCI' is rare or non-existent at present. Research into possible therapies is under way, however, and it should be kept in mind that recovery might, in the future, become a (very satisfactory) new way of leaving the prevalent population.

Figure 3: Spinal cord injury case flows



System components

Case definition

The Walsh system case definition was, implicitly, all cases admitted to the six Australian SUs. If the objective of surveillance is to measure the total incidence and prevalence of SCI, adoption of more formal and comprehensive definitions is required.

A definition of new SCI cases recommended by the Centers for Disease Control (CDC) in the United States is conceptually clear, and has the advantage of making Australian incidence data comparable with that from other countries. The definition is as follows:

i) A person who suffers an acute, traumatic lesion of neural elements in the spinal canal, resulting in any degree of sensory deficit, motor deficit, or bladder/bowel dysfunction. The deficit or dysfunction can be temporary or permanent. (Intervertebral disc disease should not be included)[23].

Note that this definition applies only to newly incident cases of SCI. Variations on this definition are necessary for other purposes:

ii) Early SCI deaths: A person who, at the time of death, was known to meet the CDC clinical definition or in whom post mortem examination reveals pathophysiological evidence of a traumatic lesion of the neural elements of the spinal cord likely to have resulted in any degree of sensory deficit, motor deficit or bladder/bowel dysfunction had the person survived.

iii) Persisting SCI case: A person who meets the CDC clinical definition three months after the date of traumatic injury.

In addition, definitions are required for two groups of people who do not sustain SCI:

iv) Potential SCI case: A person who suffers an acute, traumatic lesion of non-neuronal elements of the spinal canal capable of resulting in lesion of neural elements which is avoided through adequate retrieval and clinical care (i.e. does not satisfy CDC definition at any stage).

v) Suspected SCI case: A person whose exposure to acute trauma leads to suspicion that SCI may have occurred or may occur. On assessment, no evidence is found of SCI or of spinal canal injury placing the person at risk of SCI.

Data set

Three levels of data were referred to by interviewees: a core data set for routine surveillance to be collected nationally; a set of agreed data items reflecting topical issues that would be collected for defined periods; and data items collected in order to satisfy the research interests of individual SUs. There was agreement that a core data set should be defined, and that its size should be modest. A draft data set was endorsed by SU Directors. The proposed core data set is shown in Appendix IV. Items are divided into identifiers, socio-demographic information, service and administrative data, and clinical (and public health) data It conforms to definitions contained in the National Health Data Dictionary[24]. Adoption of the NHDD standard permits several advantages: data may be obtained directly from hospital inpatient statistics collections; links to other data sets using the same format will be facilitated; and international comparisons would also be made possible, as the NHDD standard also conforms to international standards presently being developed[25]. The data set also conforms to the National Minimum Data Set for Injury Surveillance (NMDS-IS)[26], which has been developed by NISU.

Oversight

The annual meeting of the Australasian branch of IMSOP would be a suitable forum for periodic review and planning concerning SCI surveillance, provided the section of the meeting dealing with this matter was open to others interested in SCI surveillance (advocacy groups, NISU, etc).

SCI Surveillance by Spinal Units

All admissions to participating spinal units should be registered. Admissions comprise new cases of SCI, suspected and potential new SCI cases, and persisting cases of SCI readmitted for some reason.

The overall number of cases that the SUs will register is not onerous. Based on an annual incidence of 360 cases and 1200 re-admissions[27], the expected numbers in each SU are 5 incident cases and 20 re-admissions per month, respectively.

Certain information remains unchanged (e.g. date of birth, circumstances of spinal cord injury), and need only be collected on the first occasion that a person's information is added to the register. Other information may change, and should be collected during each admission (e.g. marital status, reason for admission).

New Cases

For the purposes of data collection, 'potential SCI' and 'suspected SCI' cases should be treated the same as 'new SCI' cases. All three groups are called 'new cases' in the following paragraphs.

The full surveillance data set should be collected on new cases. Data on new cases should be collected by the SUs during routine admission procedures. A suggested *pro forma* of data items and flow chart defining the registration process to collect this information is presented in Appendix IV.

As the patient is registered, data referring to the characteristics of the person being admitted (sociodemographic), the reasons for admission, and the level of injury should be recorded. Other details may be obtained from clinicians and the patient during the inpatient stay. The final stage of data collection occurs with discharge, when information on final diagnoses, functional state, discharge date and mode of separation is recorded.

Many of these data may also be available from the inpatient statistics collections, which are now maintained by Australian hospitals. Data may be obtained by SUs from medical records departments. The future direct acquisition of data (i.e. by direct transfer from hospital computer to SU computer system) is also worth investigating.

Persisting cases of SCI

As defined above, a persisting case of SCI is a person who meets the CDC clinical definition of SCI three months after the date of traumatic injury. Persisting cases may be admitted to a SU on several occasions over a long period of time.

If a persisting case is known to have been registered previously in the surveillance system, then at subsequent admissions only a short data set need be collected, consisting of items which may change over time. If a persisting case has not been registered previously in this system, then the full surveillance data set should be collected, as for a new case.

The short data set includes unit and patient identifiers, the reason for the re-admission, the presence of other complications, admission and discharge dates, and indicators of well-being that include compensation status, marital and employment status, and occupational status. A short case data form and flow chart of the registration process is presented in Appendix IV.

Other aspects of SCI surveillance

It has been emphasised that some new SCI cases may not be admitted to a SU. Thus, monitoring of cases admitted elsewhere needs also to be addressed. It is suggested that links between SUs and doctors treating SCI outside SUs should be initiated through the development of a system of notification.

It is likely that any paediatric SCI cases not treated in an SU will be treated in a specialist children's' hospital. As the number of these is few (occurring only in the largest metropolitan areas), direct links should be established between SUs and the paediatricians most likely to care for neurological cases. As they are identified, the surveillance system should be explained to them, and they should be requested to notify SUs of cases coming to their attention using the *pro forma*. Follow-up could be based on a periodic telephone call by SUs to these doctors. Depending on the response and yield of cases, this could then be modified to a more passive system of notification.

In addition to monitoring the occurrence of these cases, useful contact between SUs and the clinicians could also be made, to enable better and more informed treatment of these young patients. It should again be noted that the number of these cases is thought to be small—but they do represent a population whose future needs for rehabilitation and services are distinct from the general SCI population. As the SUs are notified of these cases, they should in turn be referred to NISU for data entry.

It may be possible to check the completeness of notification by examining State inpatient separation files, looking for cases coded to ICD-9-CM codes 806 (fracture of vertebral column with SCI) and 952 (SCI without evidence of spinal bone injury), and identifying those which appear to be new cases

Early mortality

In SCI cases who do not survive to be admitted to an acute care facility, death may occur instantly or after a short period. It is of interest to obtain data on the nature and circumstances of the injury, because it may be used to determine whether such deaths may be averted. The use of a national coronial database[28], which records the results of investigations of violent or unexpected deaths, would enable this area of SCI epidemiology to be addressed, and the rate of such deaths to be measured.

A case definition for this purpose is problematic. For incident cases, the presence of a neurological deficit is utilised. For the deceased case this cannot be used, and some other criterion of SCI is required.

Because of its involvement in developing the Coronial database at the national level, NISU could obtain and report these data. Data sought should as much as possible match that obtained for new cases admitted to a SU, so that comparisons may be made between the two populations (see Appendix IV).

Establishing the prevalence of SCI

The starting point for a prevalence register should be the Walsh register. About 4300 incident cases have been recorded on this database. These have been obtained through historical case ascertainment from the records of SUs, and through the addition of incident cases admitted to SUs from 1986 to the end of 1992. All data already existing within the Walsh system should, as far as possible, be incorporated into the new database.

There are three areas in which people with SCI are not represented on the Walsh register. The first of these, which has always prevailed, concerns cases which occurred while the Walsh system was in operation, but not admitted to a SU. The second is people whose injury occurred before the Walsh register commenced operation, and who did not have any contact with a SU while the register was operating. The third area of non-coverage is injuries which have occurred since the Walsh system ceased operation.

Conducting an SCI census would enable these cases to be recruited to an SCI prevalence register. Funding would be necessary to conduct the census and maintain the prevalence register once established.

The SCI census should be conducted in consultation with the SCI support and advocacy groups. Direct involvement of the SCI community would enable its response to the project to be gauged, concerns addressed, and the benefits of the project put forward.

Late mortality

Case definition: Any person on the prevalence register who dies, from whatever cause.

Data set: Essential data to be collected are case identifiers, the notification source, the date and the cause of death. The latter may be obtained as a text description from death registers, together with an ICD-9 code. It may be useful to record definitive information on social well-being indicators also; these include compensation and marital status, whether employed or not, and occupation. A suggested form which may be used to notify deaths is presented in Appendix IV.

Data collection and collation: If a national prevalence register is established, the main method of mortality surveillance would be to routinely compare the prevalence register with the National Death Index—an activity that can be carried out by NISU. Depending on the yield from informal notifications and this method, the comparisons may be made annually or biennially.

SU's also become aware of the deaths of some prevalent SCI cases through informal sources, such as newspaper death notices, and from relatives of the deceased seeking to return wheel-chairs. It is suggested that these sources continue to be utilised, and that the contribution of support and advocacy groups towards the monitoring of deaths also be recognised. The existence of informal links between SUs and the support groups was noted during the review, and it is suggested that these be raised to a more formal understanding. It is further suggested that the groups routinely inform SUs of deaths coming to their knowledge by using the notification form, and that SUs should similarly inform the support groups. If the information is in the public domain (i.e. published within death notices) there is no difficulty associated with this interchange of information.

Data collation, analysis and reporting

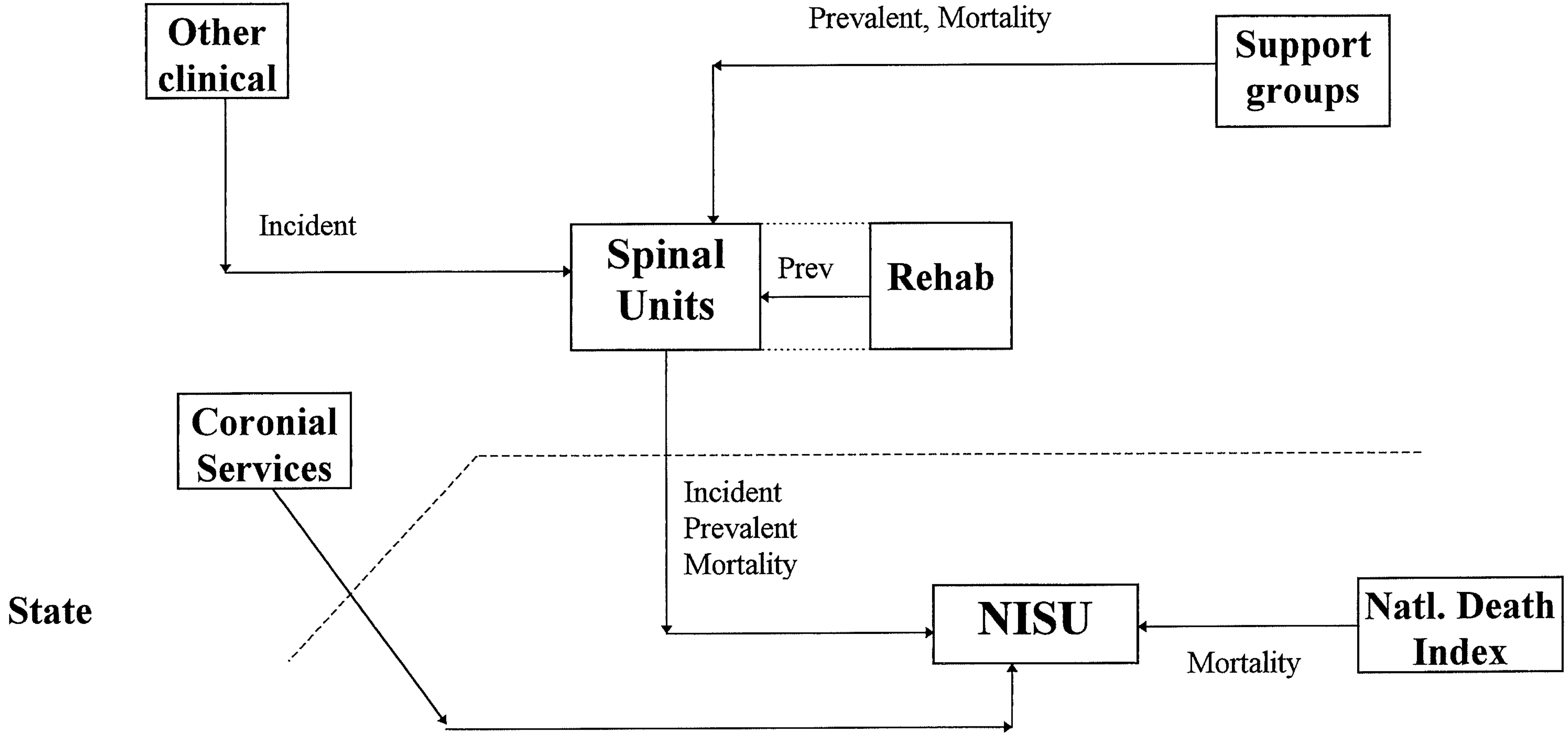
A possible overall scheme for surveillance information flow is shown in Figure 4.

For the successful long-term operation of the surveillance system, it is essential that a computerised system of data management be developed. Registration and notification of incident cases may commence before this occurs.

The nature and timing of reporting should be established as the system develops. Initially, SU's should send case forms to NISU periodically. NISU should provide specific summary reports to each SU, perhaps each two months. An annual statistical report should be produced. The annual report should provide a broad picture of the occurrence of SCI, and also provide an introduction to more detailed analyses obtained from a national SCI database. It should contain analyses of SCI incidence, prevalence, and mortality as such information becomes available. It might include temporal trends and State-based information and broad causative analyses. Additionally tables of SCI occurrence by age, gender and injury levels, together with information which measures the impact of SCI on health services (*e.g.* numbers of admissions, LOS statistics, complications experienced, according to injury level) should be reported. More detail on reporting is presented in Appendix VI.

As part of a strategy to maximise the use made of surveillance data, regular reporting on the activities of the surveillance system should be published. Although contributors to the review suggested a separate newsletter, production of this may be hard to justify during the early stages of the surveillance system's existence. News of SCI surveillance activities may be more profitably submitted to NISU's *Injury Issues Monitor*. There does remain scope for more directly informing the SCI community of the activities of surveillance. This can perhaps be further pursued through the newsletters of the support and advocacy groups, such as Quadcare, or health publications, such as Health Indicators Bulletin.

Figure 4: Data flow for surveillance of SCI



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Appendices

Appendix I: List of meetings held, and persons consulted

Place of Meeting	Persons Consulted
Royal North Shore Hospital Spinal Unit	Dr Sue Rutkowski, Mr John Walsh, Dr James Harrison, Dr Sue Quine, and Ms Fran Page-de-Mars
Coopers and Lybrand	Mr John Walsh
Prince Henry Hospital Spinal Unit	Dr Stella Engel
Royal Adelaide Hospital Spinal Unit	Dr Ruth Marshall
Royal North Shore Hospital Spinal Unit	Dr Sue Rutkowski, Ms Fran Page-de-Mars
National Injury Surveillance Unit (Adelaide)	Dr James Harrison
Royal Rehabilitation Centre (Sydney)	Dr John Yeo, Professor Dennis Smith, Dr R Oakeshott, Mr George Truman, Mr John Rothwell, Ms Tina Magennis
Royal Perth (Rehabilitation) Hospital Spinal Unit	Mr John Ker
Paraplegic and Quadriplegic Association of Western Australia	Mr Nigel Glass
Paraplegic & Quadriplegic Association (Paraquad) of NSW	Mr Bob Duncan, Mr Chris Campbell
Prince Henry Hospital Spinal Unit	Professor Richard Jones, Dr Stella Engel
Motor Accidents Authority (NSW)	Ms Anne Deans, Ms Susan Ferguson
Princess Alexandra Hospital Spinal Unit	Dr Vernon Hill, Dr Sue Urquhart
Health Department, New South Wales	Dr David Lyle
The Menzies Foundation, Melbourne	Dr Eric Wigglesworth
Austin Hospital Spinal Unit	Dr Doug Brown
Monash University Accident Research Centre (MUARC))	Dr Joan Ozanne-Smith
Australian Quadriplegic Association	Ms Felicity Purdy

Appendix II: Meeting protocol

Background

- Development of Australian Spinal Cord Injury System database by John Walsh

- Discontinuation of funding by major supporters

- Interest of Australian Institute of Health and Welfare in the continuation of the System

- Decision to conduct a review, to examine particularly: the nature and extent of support for the continued operation of the System; the definition of practicable and acceptable means for satisfying information needs that may be identified.

Process

To conduct meetings with Spinal Units, and other interested parties, in order to obtain information that will allow these questions to be answered.

That in these meetings, points of discussion include:

- the overall perception of the present System;
- the System's objectives;
- its operation, from both User and Provider points of view;
- new and outstanding issues in spinal injury, that will define the System's future objectives;
- the issues that will determine how the System might operate;
- consider the resources that will be required for the successful operation of the System.

That prior to the meeting a list of general questions be circulated to the Directors of Spinal Units and other interested parties, and that these, together with more specific questions from the interviewer, form the basis for discussion

Overall views

Would you like to make any general comments on the surveillance of spinal injury (SI) in Australia?

Overall objectives - present

1. What do you think have been the benefits of the Australian Spinal Injury Surveillance System (the System) ?

2. The first recommendation of the second Menzies' Foundation meeting was that a register of spinal injury be established, to provide information on:

    - Incidence, morbidity, mortality
    - Causation
    - Outcomes and long term consequences of SI
    - Needs of people with SI?
    - How has the present System met these objectives?

3. What have been the most important contributions towards each of these aims?

Overall objectives - future

1. Do these original objectives need changing?

2. What now are the important issues in spinal injury?

3. Are there issues that fall outside these objectives?

4. Can the objectives be altered to better define the operation of a register or surveillance system?

Utility

1. What are your principal needs, and how does the System address them? What information is necessary to meet these needs?

2. What questions or issues have you been able to answer or decide, using data obtained from the System?

3. Have you had questions for which data were not available - Were you able to answer them in some other way?

4. Can you see new needs that may be placed upon the System - How might these be addressed?

Operation - how the System works - present

1. Has the System operated satisfactorily in obtaining and delivering the data you need?

2. Does the System operate efficiently? Are the data easily collected? How much effort is involved in filling in forms?

3. If asking questions is data to answer them easily obtained from the database?

4. Of what use have the annual reports produced by Quad-Care[i] been to your work?

5. Has the System collected information on the right cases - is it sensitive (consider trauma/non-trauma for instance) ?

6. Do you think that the data that are collected are appropriate?

7. How acceptable are the forms to the people obtaining the data, or the patients who provide the information?
8. How simple is the System?

9. How straight-forward is the collection of data - can it be obtained from simple sources?

10. Once data are in the System, how accessible are they?

11. Can questions requiring data be easily answered?

12. Is information obtained from the System timely enough for your purposes -what are these constraints?

13. Has the System been able to obtain new information in response to a new or changing issue - is it flexible?

Operation - future use

1. How might the System be improved?

2. Can you see ways in which data collection might be improved?

3. Where best is it to collect information on spinal injury?

4. Should other sources of data be utilised? How might these be accessed?

5. Where should the data be stored?

6. What kinds of data should be collected - what do you need to know about in order to address the issues of importance to you?

7. Should the present data set be amended - are parts in need of reduction or expansion?

8. Should information be collected on all cases of spinal injury?

9. What about non-trauma cases?

10. What about cases of spinal injury that are not admitted to a spinal unit?

11. How might its utility or access to the System be improved?

12. Should routine reports be produced?

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[i] Actuarial Research Into Physical Disability

13. What should they contain? How often should they appear?

14. What else do you think is necessary for the successful operation of the System?

National reporting of SI

Much of the discussion has been about a system which could instead be configured as a number of separate state-based databases.

1. Is there a distinct rôle for a national data set? What should that rôle be?

2. What should be available from such a system?

3. Where could it be based, and who should look after it?

4. Should it contain all the data that spinal units collect?

Conclusion, and future operation

We've spoken a little about how surveillance of spinal injury presently operates.

1. If surveillance of spinal injury is to continue, it must address important issues. What are these issues?

2. Can the issues be efficiently addressed - how should surveillance best operate so that these aims can be achieved?

Appendix III: Requests for Information

Name	Date	Need
Anita Mottau, CRS	05/07/90	Analysis of CRS SCI clients
Lesley Hickey, CRS	05/07/90	Analysis of CRS SCI clients
Julie Pryor, Moorong	10/10/90	Thesis
Mark Arronson, A/G	11/10/90	Dowd request for info
Sylvia Bartolo, RTA	17/10/90	Crash Lab–Bike accidents
Nigel Glass, WA PQA	25/10/90	Justify funding
Fidye Westgarth	12/11/90	MPH Thesis
Nicki Bell, RNSH	26/11/90	Assessment for physio staff
Upjohn–Tish Holliday	26/11/90	Medication promotion
MAA	29/11/90	Presentation to insurers
AQA–Barbara Quintrell	11/12/90	C4 and above–incidence & prevalence
John Yeo	15/12/90	Figures & Graphs for SCI India paper
Patsy, Moorong	11/12/90	Copies of Bulletin
Ms Julie Wilson, CRS	08/01/91	Assistance and comparative figures on Asian epidemiological experience for SCI
Mr Bob Duncan, Paraquad	10/01/90	Survey details for accommodation preferences of people who have sustained SCI
WA Solicitor	15/01/91	Information on SCI expectation of life
Mr Corrick	23/01/91	Listing of ARIPD in 'IDEAS' disability database
Deborah Moran, PA	23/01/90	Request from QLD community nurses for names and addresses of recently discharged (1989/90) SCI patients
Tamworth Base Hospital		University of New England Masters students
Michelle Redfern Cumberland College OT	04/02/91	Information for Study and Assignments
Ian Armstrong-Taylor, TGS Electronics, South Australia	12/02/91	Information on Incidence rates
Dr Ruth Marshall, Royal Adelaide Spinal Unit	14/02/91	Incidence rates of DVT and Pulmonary Emboli
Chris Seeto, ICU	25/01/91	Information for

continued

Name	Date	Need
Dr Ruth Marshall, Royal Adelaide Spinal Unit	14/02/91	Breakdown of SA quadriplegics by Neuro-level and Frankel classification - for assessing statistical significance.
Dr Peter Flett, Regency Park SA Regency Park SA	15/02/91	Incidence Rate of Paediatric SCI
Dr Peter Flett, Regency Park SA Regency Park SA	15/02/91	Life Expectancy of People who have sustained SCI
Ms Veronica Fuss, Company Doctor P/L Chatswood NSW	18/02/91	Information on rehabilitation for 'Australian Doctor' magazine
Dr Vernon Hill, Princess Alexandra Spinal Unit	20/02/91	Reclassification of SCI into Falls and Crush Accidents
Ms Susan Hoare c/- Nurses Home Moree Hospital	26/02/91	Incidence & Outcome Information for Thesis
Ms Wendy Jennings, Sydney Home Nursing RNSH	04/03/91	Information on Incidence and Onset Details of SCI
Mr Joe Schipp, NSW Minister for Housing	07/03/91	Information on nursing home accommodation
Mr Garry Holland, St George Hospital	14/03/91	Incidence Rates for Nurse Education
Dr Miranda Jelbart, Royal Adelaide Hosp	20/03/91	Road trauma incidence rates for TV awareness campaign
Ms Felicity Purdy, AQA	22/03/91	Information on car usage to help Telecom in assessing the demand for mobile phones
Ms Carolyn Wright, Northern Territory	22/03/91	Incidence, mortality and morbidity data for BSc (nursing) thesis

Appendix IV: Proposed data sets for SCI registration

A. Proposed incident case data set: SCI registration of new cases

Item	NHDD	NMD-IS	Comments
Identifiers			
Establishment identifier	P1	General	Can be got from unit name. NHDD code for spinal cord injury unit is E4.10
Patient identifier	P2		Medical record no.; ?Name; ?Code (2+2/DOB)
Sociodemograhic			
Sex	P4	General	
Date of birth	P5	General	
Address			Would provide NHDD item P9 (area of usual residence)
Aboriginality	P7	General	
Marital status	P8		
Country of birth	P6	General	Preferred language (P11), period of residence in Aust (P12), and need for interpreter (P13) are 'Excluded' NHDD items.
Employment status	P14	General	
Occupation	P15	General	ASCO, to 2-digit level
Education level attained			
Service and administrative			
Compensable status	P18		Yes/No. Also?; source (3rd party, workers, other), status (pending, settled, structured, lump sum) of compensation; hospital insurance status (P19).
Admission date	P24	General	
Discharge date	P26		Length of stay derived as P26-P24
Mode of separation	P31		Includes vital status.
Clinical (and public health)			
Principal diagnosis	P35	Core	P35 is the chief reason for the admission, as determined at time of discharge, coded to ICD9-CM. In this setting the item would initially be the 'currently assessed' chief reason, update, if necessary, at discharge.
Additional diagnoses (include operative procedures)	P36		Conditions other than principal diagnosis, including those present at time of admission or arising during stay (can include complications of care).
Reason for admission (text)			*e.g.* 'Acute management of unstable cervical spinal fracture.'

continued

Item	NHDD	NMD-IS	Comments
Traumatic/non-traumatic			Whether condition damaging spinal cord, or placing it at risk, was mainly due to acute, external trauma (*e.g.* motorcycle crash), or due to disease process (*e.g.* collapsed vertebra due to metastatic carcinoma).
Level of injury; Complete/incomplete			Need for detail beyond that in ICD9-CM? (*Nb.* Codes 805, 839, 806, 952).
Text description of event		Core	Brief description of circumstances of injury.
External cause of injury	P39	Core	P39 requires full ICD9-CM E-coding. NMD-IS offers a simpler, consistent method.
Activity at time of injury		Core	Short item, from 10th revision of ICD.
Type of place where injury occurred	P40	Core	NMD-IS and NHDD codes both compatible with ICD9; NMD-IS also compatible with ICD-10.
Place where injury occurred		Suppl	Postcode, or ASGC units.
Date and time of injury		General	To nearest hour
Health status at discharge			Level of rehabilitation attained? Functional status score? General health indicator? (e.g. SF-36).

Abbreviated Injury Scores (AIS), and an Injury Severity Score (ISS) are desirable - may be available from trauma services providing initial management. Indicators of intoxication, especially by alcohol, are desirable, and will often be available (road crash cases).

Case Registration Form

For new cases of SCI admitted for first time, and cases being readmitted who are un-registered

Identifiers

NISU SCI Registration Number:

1. Spinal Unit: .... U.R. Number: ....
SU abbreviation

2. Patient: ....
Surname First name MI

Sociodemographic items

3. Sex: ....
1 = Male 2 = Female 9 = Unknown

4. Date of birth: ....
DD/MM/YYYY

5. Country of birth: ....

6. Aboriginality: ....
1 = Aboriginal or Torres Strait Islander
2 = Other

7. Marital status: ....
1 = Never married 2 = Widowed 3 = Divorced
4 = Separated 5 = Married (including *de facto*)
6 = Not stated/inadequately described

8. Highest education level attained: ....
1 = Primary school 2 = Secondary school 3 = Tertiary, trade certificate
4 = Tertiary, degree If 3 or 4, **specify:**.................................

9. Employment status: ....
1 = Employed 2 = Pensioner 3 = Unemployed

10. Occupation: ....
see coding manual

11. Current address: ....
....
....
Postcode

Inpatient episode

12. Reason(s) for this admission: ....
....
....

13. Compensable status: ....
1 = Compensable 2 = Non-compensable
If 1, specify:__________________

14. Admission Date:
....
DD/MM/YYYY

15. Principal diagnosis: ....
....
ICD-9-CM

16. Additional diagnoses: ....
....
....
ICD-9-CM

17. Level of injury: ....
....
Complete/incomplete
Circle one

18. Discharge date:
....
DD/MM/YYYY

19. Mode of separation (Discharge/Transfer): ....
1 = To an(other) acute hospital 2 = To a nursing home 3 = To an(other) psychiatric hospital 4 = To other health care accommodation 5 = Statistical discharge–type change 6 = Left against medical advice / discharge at own risk 7 = Statistical discharge from leave 8 = Died 9 = Other (usual residence/own accommodation/welfare institution)

20. Health status at discharge (functional level attained):
....
....
....

21. Cause of SCI: Trauma/disease
Circle one
If trauma, complete questions 22–27

Hospital Use

Event resulting in SCI

22. Description of event leading to injury (include <u>place</u> and <u>activity</u> at the time of injury, and main external cause): ....
....
....
....
....
....
....
....

23. Street address or postcode of place where injury occurred: ....
....
.... ☐☐☐☐
Postcode

Questions 24–29, see coding manual

Main Ext cause A: .... ☐☐
Main Ext cause B: .... ☐☐
Type of Place: .... ☐☐
Type of Activity: .... ☐☐
Date of injury: .... / /
Time of injury: .... ☐☐
HH

Minimum classifications for Core Data Items

Version 1.0 (as at October 1993)

2A. Main 'external cause' of injury

1.	Motor vehicle - driver
2.	Motor vehicle - passenger
3.	Motorcycle - driver
4.	Motorcycle - passenger
5.	Pedal cyclist and cycle passenger
6.	Pedestrian
7.	Horse related (fall from, struck or bitten by)
8.	Other transport-related circumstance
9.	Fall - low (same level, or < 1 metre, or no information on height)
10.	Fall - high
11.	Drowning, submersion - swimming pool
12.	Drowning, submersion - other
13.	Other threat to breathing (incl strangulation, asphyxiation)
14.	Fire, flames, smoke
15.	Hot drink, food, water, other liquid, steam, gas, or vapour
16.	Hot object or substance (not food, liquid, gas)
17.	Poisoning - medication
18.	Poisoning - other or unspecified substance
19.	Firearm
20.	Cutting, piercing object
21.	Dog related (bitten, struck by, etc)
22.	Animal related (except horse, dog)
23.	Struck by object or person
24.	Machinery in operation
25.	Electricity
26.	Hot conditions (natural origin); sunlight
27.	Cold conditions (natural origin)
28.	Other specified external cause
29.	Unspecified external cause

2B. Most likely role of human intent

1.	Accident
2.	Intentional self-harm
3.	Sexual assault
4.	Neglect or maltreatment by parent or guardian
5.	Maltreatment by domestic partner
6.	Other assault
7.	Event of undetermined intent
8.	Legal intervention, or operations of war
9.	Adverse effects or complications of medical or surgical care or treatment
10.	Other specified intent
11.	Unspecified intent

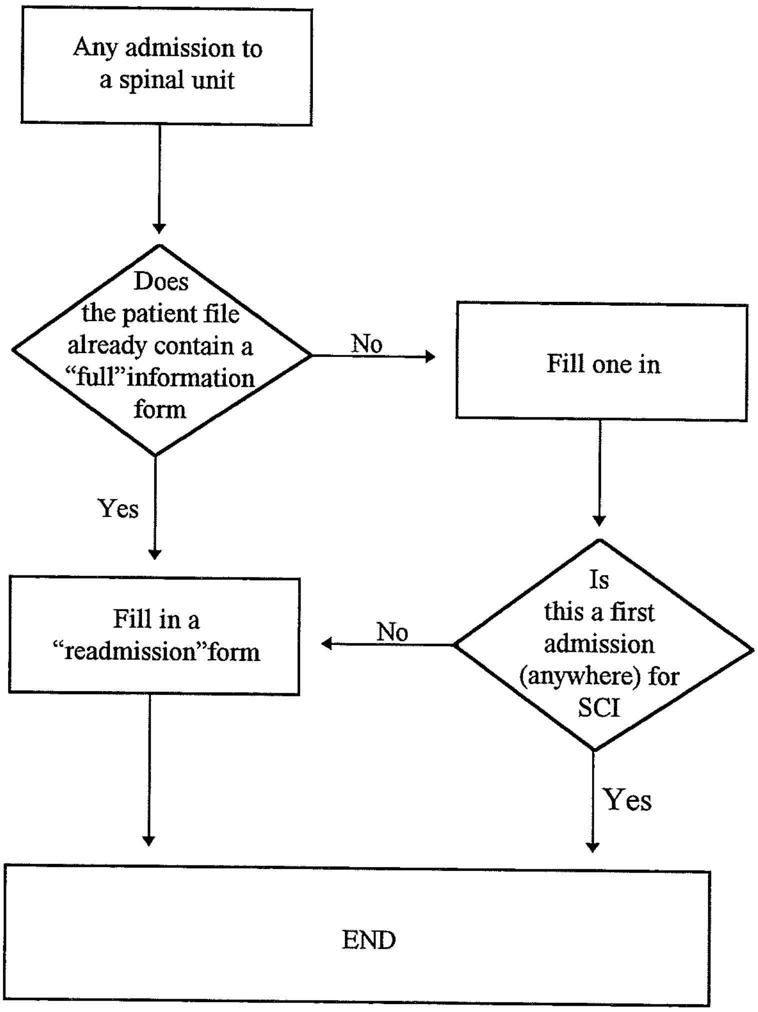
3. Type of place where injury event occurred

1.	Home (incl. farm-house)
2.	Residential institution (excl. hospital; incl. hospice, prison)
3.	School, other institution, public admin. area (excl. hospital; incl day care centre)
4.	Hospital
5.	Recreation area (eg amusement park, public park)
6.	Sports and athletics area (eg football arena, riding school)
7.	Street or highway (incl adjacent footpath)
8.	Trade or service area (eg bank, petrol station, supermarket)
9.	Industrial or construction area
10.	Mine or quarry
11.	Farm (excl. farm house)
12.	Other specified place (incl forest, beach, abandoned building)
13.	Unspecified place

4. Type of activity of the person when injured

0.	Sports activity
1.	Leisure activity
2.	Working for income
3.	Other type of work (incl unpaid housework, related shopping, etc)
4.	Resting, sleeping, eating, other personal activity
5.	Being cared for (eg infant by parent; patient by nurse)
6.	Engaged in formal educational activity (as student)
8.	Other specified activity
9.	Unspecified activity

Spinal Unit SCI Case Information Flow Chart



B. Proposed prevalent case data set

Rehabilitation and readmission

Unit/centre name
Patient identifier
Reason for (re)admission (readmission, tx of complication,)
Admission date
Functional Level attained (modified Barthel Index/ UDS FIM)
Date discharged

Indicators of social well-being

Compensation status
Marital status
Employment status
Occupation

[†] Obtain updated information on these at each admission

Readmission Form

For updating information on cases being readmitted; if case un-registered, complete Case Registration Form

Identifiers

NISU SCI Registration Number:

1. Spinal Unit: ....
SU abbreviation

U.R. Number: ....

2. Patient: ....
Surname First name MI

Sociodemographic items

3. Marital status: ....
1 = Never married 2 = Widowed
3 = Divorced 4 = Separated
5 = Married (including *de facto*)
6 = Not stated/inadequately described

4. Employment status: ....
1 = Employed 2 = Pensioner
3 = Unemployed

5. Occupation: ....
see coding manual

6. Current address: ....
....
....
Postcode

Inpatient episode

7. Reason(s) for this admission: ....
....
....
....
....

8. Compensable status: ....
1 = Compensable 2 = Non-compensable
If 1, specify: ____________________

9. Admission Date:
....
DD/MM/YYYY

10. Principal diagnosis: ....
....
....
ICD-9-CM

11. Additional diagnoses: ....
....
....
....
....
ICD-9-CM

12. Discharge date: ....
....
DD/MM/YYYY

13. Mode of separation (Discharge/Transfer):
....
1 = To an(other) acute hospital 2 = To a nursing home
3 = To an(other) psychiatric hospital 4 = To other health care accommodation 5 = Statistical discharge–type change
6 = Left against medical advice / discharge at own risk
7 = Statistical discharge from leave 8 = Died
9 = Other (usual residence/own accommodation/welfare institution)

14. Health status at discharge (functional level attained): ....
....
....
....

Hospital Use

C. Proposed Mortality case data set

Patient identifier
Notification source (establishment identifier, notifier)
Date of death
Cause of death (Text from death register and ICD9 code)

Definitive information on some indicators of social well-being, at the time of death:

Compensation status
Marital status
Employment status
Occupation

Death of SCI Case

Identifiers

NISU SCI Registration Number:

1. Spinal Unit: .... U.R. Number: ....
SU abbreviation

2. Patient: ....
Surname First name MI

3. Notification source: ....
Establishment identifier; notifier

4. Death date: ....
DD/MM/YY

5. Cause of death: ....
....
....
....
....
....

(Text from death register; ICD-9 code)

Definitive information on the following indicators of well-being at the time of death:

6. Functional level attained: ....
....
....
....

7. Marital status: ....
1 = Never married 2 = Widowed 3 = Divorced 4 = Separated
5 = Married (including *de facto*) 6 = Not stated/inadequately described

8. Employment status: ....
1 = Employed 2 = Pensioner 3 = Unemployed

9. Occupation: ....
see coding manual

Remarks: ....
....
....
....
....
....
....
....
....
....

Appendix V: Previous (Walsh) data set

A1 AUSTRALIAN SPINAL CORD INJURY REGISTRY Page 1 of 1
30/1/90

SPINAL UNIT:

PATIENT FAMILY NAME:
GIVEN NAMES:

HOSPITAL UNIT NUMBER:
FORM COMPLETED BY:

OTHER REFERENCE NUMBER:
DATE: / /
(dd/mm/yy)

FORM A1:

PRE-ACCIDENT HISTORY (to be completed at FIRST ACUTE admission)

Personal details:

1. Date of Birth: / /
   (dd/mm/yy)
2. Sex: M / F

Ethnicity:

3. Country of Birth:
4. Primary Language:
5. Aborigine/TSI: Y / N

Residence at Date of Onset:

6. Address:
7. Town:
8. Postcode:
9. Contact Phone Nos: ( )
   ( )
   ( )
   STD

Dependency Status:

10. Marital Status:
    1. Never Married
    2. Now Married (include defacto)
    3. Divorced
    4. Separated (not divorced)
    5. Widowed
11. Living Status:
    1. Living Alone
    2. Living with Spouse/Partner
    3. Living with parent (s)
    4. Living with Dependent Family
    5. Living with Other Family
    6. Friends
    9. Other
12. Number of Dependents:
    1. Own Children aged 15 or less ☐
    2. Own Children aged 16 or more ☐
    3. Others aged 15 or less ☐
    4. Others aged 16 or more ☐

Work Force Participation at Onset:

13. Work Force:
    1. Not in WF
    2. Full Time
    3. Part Time
14. Main Source of Income:
    1. Self employed
    2. Sheltered/Supported employment
    3. Wages & Salary (Public Sector)
    4. Wages & Salary (Private Sector)
    5. Employer
    6. Unpaid Helper
    7. Currently Unemployed
    8. Retired/Aged Pensioner
    9. Full Invalid Pensioner
    10. Domestic Duties
    11. Pre-school
    12. School Student
    13. Other full time study
    14. Other Benefits
    15. Job Training / Placement
    16. Part invalid pensioner
    19. Other (please specify)
    ....
15. Main Job Occupation (if in WF):
    ....
16. Industry of Main Job Occupation:
    ....

Attained Education at Onset:

17. Highest level of Education:
    1. Tertiary / Post Graduate
    2. Trade Qualific'n / Apprentice
    3. Diploma or Certificate
    4. Other Post-school study
    5. Highest available school level
    6. Left school aged 16 or over
    7. Left school aged 15 or less
    8. Never attended school
    9. Still at school

A1 AUSTRALIAN SPINAL CORD INJURY REGISTRY Page 1 of 1
30/1/90

SPINAL UNIT:
PATIENT FAMILY NAME:
GIVEN NAMES:

HOSPITAL UNIT NUMBER:
FORM COMPLETED BY:
OTHER REFERENCE NUMBER:
DATE: / /
(dd/mm/yy)

FORM X1:

ACCIDENT DETAILS (to be completed at FIRST ACUTE admission)

1. Location of Accident:
    1. Capital City
    2. Country City
    3. Country (rural)
    4. Overseas
2. Site of Accident:
    1. Non-Traumatic
    2. Workplace
    3. School, College, etc
    4. Own Home
    5. Street, Road, Highway
    6. Leisure Venue
    7. Other Domestic Home
    9. Other (please specify)

……

3. Date of Injury or onset of Symptoms:
/ /
(dd/mm/yy)

4. Cause of Non-traumatic Spinal Cord Injury
    1. Spina Bifida
    2. Congenital
    3. Poliomyelitis
    4. Vascular
    5. Transverse Myelitis
    6. Tumour
    7. Infection
    8. Disc Lesion
    9. Multiple Sclerosis
    10. Cerebral Palsy
    19. Other non-traumatic

……

5. Cause of Traumatic Spinal Cord Injury
1. Motor Car Accident
2. Motor Bike Accident
TRANSPORT 3. Motor Truck Accident
4. Pedal Bike Accident
5. Public Transport
6. Diving
WATER 7. Water Skiing
8. Other Water Sports
9. Rugby League
10. Rugby Union
11. Australian Rules
12. Soccer
13. Horse riding
14. Snow skiing
SPORT 15. Gymnastics
16. Trampolining
17. Athletics
18. Abseiling
19. Mountaineering
20. Other Sports
21. Stabbing
VIOLENCE 22. Gunshot
23. Physical Violence
24. Other Violence
FALLS/ 25. Fall from height (> 3 m)
CRUSH 26. Fall (< 3 m)
27. Crush by Heavy Object
28. Plane Crash
OTHER 29. Helicopter Crash
99. Other Traumatic

……

7. For Transport Accidents:
    1. Driver
    2. Front seat passenger
    3. Back seat passenger
    4. Pillion passenger
    5. Other passenger
    6. Pedestrian

    Seat Belt worn Y / N
    Helmet worn Y / N
8. Water Sports:
    1. Pool 2. River 3. Surf 4. Other
9. Football:
    1. Position
    2. Circumstances:
        (a) Tackle
        (b) Scrum
        (c) Ruck
        (d) Maul
        (e) Other

A1 AUSTRALIAN SPINAL CORD INJURY REGISTRY Page 1 of 1
30/1/90

SPINAL UNIT:
PATIENT FAMILY NAME:
GIVEN NAMES:

HOSPITAL UNIT NUMBER:
FORM COMPLETED BY:
OTHER REFERENCE NUMBER:
DATE: / /
(dd/mm/yy)

FORM A2:

INITIAL CLINICAL ASSESSMENT (to be completed at FIRST ACUTE admission)

Admission Details:

1. First Admission to this SIU: Y / N
2. Date of Admission: / /
   (dd/mm/yy)

Transfer Details:

3. Duration Since Onset of Symptoms:
   1. < 6 hours
   2. 6 - 12 hours
   3. 12 - 24 hours
   4. 1 - 7 days
   5. 1 - 4 weeks
   6. 1 - 12 months
   7. > 1 year
4. Mode of Transfer:
   0. Unknown
   1. Private
   2. Helicopter
   3. General Ambulance
   4. Air Ambulance
   5. ICU Ambulance
   6. Commercial Airline
   9. Other
5. Source of Transfer
   0. Unknown
   1. Direct from Injury/Onset/Home
   2. Other Hospital (not SIU)
   3. Other Spinal Injuries Unit
   4. Overseas

Initial Clinical Assessment:

6. Associated Injuries:
   0. None
   1. Head
   2. Chest
   3. Abdominal
   4. Pelvic
   5. Long Bone Fractures
   6. Burns
   7. Skin Lacerations
   8. Brachial Plexus
   9. Clavicle / Scapula
   10. Hypothermia
   98. Unknown
   99. Other
7. Neurological level:
   (Lowest Normal Spinal Segment)
8. Complete / Incomplete: C / I
9. Vertebral Injury: Y / N
10. Clinical Classification:
    (Frankel and Sub-Groups)
    A. Complete No Sensation or Motor Function below level of spinal lesion
    B. Sensory Sparing Only
    B1. Partial Sensory Sparing
    B2. Partial Sensory Sparing and Motor Sparing (useless)
    ..C. Motor Sparing (useless)
    C1. Central Cord Syndrome
    C2. Hemisection of Cord
    D. Motor Sparing (useful)
    E. Normal
    U. Unable to be diagnosed
11. Height: cms
    Weight kgs

A1

AUSTRALIAN SPINAL CORD INJURY REGISTRY

Page 1 of 1
30/1/90

SPINAL UNIT:

PATIENT FAMILY NAME:
GIVEN NAMES:

HOSPITAL UNIT NUMBER:
FORM COMPLETED BY:

OTHER REFERENCE NUMBER:
DATE: / /
(dd/mm/yy)

FORM A2:

CLINICAL DISCHARGE (to be completed at EACH DISCHARGE)

Discharge Circumstances:

1. Date of Discharge: / /
(dd/mm/yy

2. Major Discharge Status:
   0. Unknown
   1. Normal Discharge
   2. Transfer to Another SIU
   3. Transfer within this Hospital
   4. Transfer to Another Hospital
   5. Transfer to Rehabilitation
   6. Transfer to Transitional Home
   7. Transfer to Permanent Institution
   9. Death
   19. Other Transfer

……

During Admission:

5. Complications of paralysis:
   0. No complications
   1. Deep Vein Thrombosis
   2. Pulmonary Embolism
   3. Respiratory
   4. Renal
   5. Urinary
   6. Pressure Sores
   7. Heterotrophic Ossification
   8. Spasticity
   9. Autonomic Hyperreflexia
   10. Fracture (post onset of injury)
   11. Multiple Resistant Staphylococcus Aureus
   12. Significant Depression/Anxiety
   13. Significant Pain
   14. Disorientation
   15. Bowel Obstruction
   16. Septicaemia
   17. Epididymo-orchitis
   18. Cellulitis
   99. Other

5. Surgical and Other procedures:
   0. No procedures
   1. Non-surgical reduction
   2. Closed Manipulation
   3. Traction - Halo
   4. - Crutchfield
   5. - Other
   6. Laminectomy (decompressive)
   7. Cervical fusion - anterior
   8. - posterior
   9. Internal fixation - cervical
   10. - thor-lumbar
   11. - other
   12. Open reduction - facetectomy
   13. - other
   14. Internal instrument'n (rods)
   15. Tracheostomy
   16. Suprapubic Cystostomy
   17. deep T.U.R.
   18. Sphincterotomy
   19. Nuclear M>R>I>
   20. Cystoscopy
   21. Cystocath
   22. Bronchoscopy
   23. Intercostal Drain
   24. Lumbar Puncture
   25. Cystometry/Urodynamics
   26. Laparotomy
   27. Plastic surgery
   28. Simple Skin Closure
   29. Endoscopy
   30. Surgical Reconstruction
   31. Sigmoidoscopy/Colonoscopy
   32. IVP
   99. Other (please specify)

……

Discharge Assessment

6. Neurological level:
(Lowest Normal Spinal Segment)

7. Clinical Classification:
   - A. Complete No Sensation or Motor Function below level of spinal lesion
   - B. Sensory Sparing Only
   - B1. Partial Sensory Sparing
   - B2. Partial Sensory Sparing & Motor Sparing (useless)
   - C. Motor Sparing (useless)
   - C1. Central Cord Syndrome
   - C2. Hemisection of Cord
   - D. Motor Sparing (useful)
   - E. Normal
   - U. Unable to be diagnosed

A1 AUSTRALIAN SPINAL CORD INJURY REGISTRY Page 1 of 1
30/1/90

SPINAL UNIT:

PATIENT FAMILY NAME:
GIVEN NAMES:

HOSPITAL UNIT NUMBER:
FORM COMPLETED BY:

OTHER REFERENCE NUMBER:
DATE: / /
(dd/mm/yy)

FORM D1:
BASIC DISCHARGE & FOLLOW-UP INFORMATION

(to be completed for people with 1986 or 1987 onset dates)

Accommodation:

1. -----Accommodation on Discharge-----

(a) Immediate		(b) Long Term
1.	House / Flat	1.
2.	Group Home	2.
3.	Hostel	3.
4.	Aged Nursing Home	4.
5.	Spinal Nursing Home	5.
6.	Acute Hospital	6.
7.	Convalescent Hosp'l	7.
8.	Transitional Facility	8.
9.	Rehabilitation Facility	9.
19.	Other	19.

2. -----Accommodation Owned by ----

(a) Immediate		(b) Long Term
1.	Self	1.
2.	Parents	2.
3.	Other Family	3.
4.	Private Landlord	4.
5.	Public Housing	5.
6.	Spinal Association	6.
7.	Compensation Authority	7.
8.	Hospital	8.
19.	Other	19.

3. Modifications Required for Long Term:
   1. To previous accommodation
   2. To new accommodation
   3. Purpose-built Home Planned

   (0=nil, 1=need minor, 2=need major, 3=completed minor, 4=completed major)
4. Preferred Location:
   1. As at present (pre-admission)
   2. Move to: ....
      (insert place & postcode)

Community Service Plans:

5. Government & Community Services:
   1. PADP
   2. Attendant Care
   3. Home Nursing
   4. Home Care - Personal Care
   5. Home Care - Housekeeping
   6. Meals on Wheels
   7. Mobility Allowance
   8. Carer's Benefit / Pension
   9. Rental Subsidy
   10. Supported Employment All'ce
   11. Rehabilitation Allowance
   12. Isolated Patients Travel
   13. Domicillary Nursing Care Ben
   14. Home Aids
   15. Spinal Association Nurse
   99. Other Benefits......................................

   (0=not elibible, 1=not required, 2=waiting decision, 3=in place)

Compensation:

6. ----------------------Status----------------------------

(a) Income		(b) Costs
0.	No Compensation	0.
1.	In Payment	1.
2.	Settled in Full	2.
3.	Part Settled	3.
4.	Still Pending	4.

Note: Record under "Income" the status of income replacement, and under "Costs" the status of reimbursement or payment for costs incurred.

7. Source:
   0. Unknown
   1. Social Welfare Only
   2. No Fault Transport Accident
   3. At Fault Transport Accident
   4. Workers' Compensation
   5. Sporting Accident Compensation
   6. Criminal Action Compensation
   7. Public liability
   8. Private Insurance
   9. Defence Forces (D.F.R.B.)
   10. Superannuation
   19. Other ....

A1 AUSTRALIAN SPINAL CORD INJURY REGISTRY Page 1 of 1
30/1/90

SPINAL UNIT:
PATIENT FAMILY NAME:
GIVEN NAMES:

HOSPITAL UNIT NUMBER:
FORM COMPLETED BY:
OTHER REFERENCE NUMBER:
DATE: / /
(dd/mm/yy)

FORM D1 (continued):
BASIC DISCHARGE & FOLLOW-UP INFORMATION (to be completed for '86 & '87 onset)

Dependency Status:

8. Marital Status:
   1. Never Married
   2. Now Married (include defacto)
   3. Divorced
   4. Separated (not divorced)
   5. Widowed
9. Living Status:
   1. Living Alone
   2. Living with Spouse/Partner
   3. Living with Parent(s)
   4. Living with Dependent Family
   5. Living with Other Family
   6. With Friends
   7. With Attendant
   8. In Permanent Institution
   9. Other
10. Number of Dependents:
    (give numbers)
    1. Own Children aged 15 or less
    2. Own Children aged 16 or more
    3. Others aged 15 or less
    4. Others aged 16 or more

Equipment Used

11. 0. No equipment used
    1. Manual wheelchair
    2. Electric wheelchair
    3. Wheelchair cushion
    4. Hand-splints (passive)
    5. Hand-splints (active)
    6. Calipers (above knee)
    7. Below knee calipers or foot-drop aid
    8. Crutches
    9. Walking stick
    10. Walking frame
    11. Body Hoist
    12. Self-lift pole
    13. Slide board
    14. Commode chair
    15. Shower chair
    16. Hospital bed
    17. Ripple mattress
    18. Water bed
    19. Sheepskin
    20. Bowel Care Equipment
    21. Urinary Equipment
    22. Bath Board
    23. Car Hand Controls
    24. Chair Hoist
    99. Other..

Work Force participation:

12. Work Force:
    1. Not in WF
    2. Full Time
    3. Part Time

13. Main Source of income:
    1. Self employed
    2. Sheltered/Supported Employment
    3. Wages & Salary (Public Sector)
    4. Wages & Salary (Private Sector)
    5. Employer
    6. Unpaid Helper
    7. Unemployment Benefits
    8. Retired/Aged Pension
    9. Full Invalid Pension
    10. Domestic Duties
    11. Pre-school
    12. School Student
    13. Other full time study
    14. Accident Compensation
    15. Job Training / Placement
    16. Part Invalid Pensioner
    17. Investment Income
    18. Superannuation
    19. Sickness Benefits
    99. Other (please specify) ....
14. Main job Occupation (if in WF): ....
15. Industry of Main Job Occupation: ....
16. Highest level of Education
    1. Tertiary / Post Graduate
    2. Trade Qualific'n / Apprentice
    3. Diploma or Certificate
    4. Other post-school study
    5. Highest available school level
    6. Left school aged 16 or over
    7. Left school aged 15 or less
    8. Never attended school
    9. Still at school
17. Address:
    Town: postcode:
    Contact phone Nos: ( )
    ( )

A1 AUSTRALIAN SPINAL CORD INJURY REGISTRY Page 1 of 1
30/1/90

SPINAL UNIT:

PATIENT FAMILY NAME:
GIVEN NAMES:

HOSPITAL UNIT NUMBER:
FORM COMPLETED BY:

OTHER REFERENCE NUMBER:
DATE: / /
(dd/mm/yy)

FORM D3:
DETAILS OF DEATH

Date of Death: / /
(dd/mm/yy)
Cause of Death:
Primary:
Secondary:
Related to Spinal Cord Injury: Y / N
Autopsy Results and Comments:

A1

AUSTRALIAN SPINAL CORD INJURY REGISTRY

Page 1 of 1
30/1/90

SPINAL UNIT:

PATIENT FAMILY NAME:
GIVEN NAMES:

HOSPITAL UNIT NUMBER:
FORM COMPLETED BY:

OTHER REFERENCE NUMBER:
DATE: / /
(dd/mm/yy)

FORM R1:

READMISSION DETAILS

(to be completed AT EACH READMISSION)

Personal Details:

1. Date of Birth: / /
(dd/mm/yy
2. Sex: M / F

Residence at Date of Admission:

3. Address:
4. Town:
5. Postcode:
6. Contact Phone Nos: ( )
: ( )
: ( )
STD

Readmission Details

7. Date of Readmission: / /
(dd/mm/yy
8. Diagnosis on Readmission:

(a) Primary		9b) Secondary
0.	Unknown	0.
1.	Deep vein thrombosis	1
2.	Pulmonary embolism	2.
3.	Respiratory	3.
4.	Renal	4.
5.	Urinary	5.
6.	Skin (pressure sores)	6.
7.	Excessive spasticity	7.
8.	Burn	8.
9.	Autonomic Hyperreflexia	9.
10.	Fracture	10.
11.	Bowel Obstruction	11.
12.	Respite	12.
13.	Reassessment	13.
14.	Haemorrhoids	14.
15.	For Elective Surgery	15.
16.	Anxiety/Depression	16.
17.	Pain	17.
18.	To Learn Self-Cath.	18.
19.	Cellulitis	19.
20.	Constipation	20.
21.	Drug/Alcohol Dependency	21.
22.	Further Rehabilitation	22.
23.	Epi-didymo orchitis	23.
99.	Other (please specify)	99.

Appendix VI: Proposed reports and contents

SU codes

WRP	Royal Perth, WA
SRA	Royal Adelaide, SA
VAN	Austin, Vic
NPH	Prince Henry, NSW
NRN	Royal North Shore, NSW
QPA	Princess Alexandra, Qld.

NISU two-monthly data report, SU specific

To ensure correct receipt of incident case notifications and data entry by NISU during the preceding two month period, NISU will list for each SU the following data items:

Surname
Forename
Date of birth
Gender
Postcode of address
Admission date
Injury level

Missing data to be identified

Two versions, one sorted alphabetically, and the other by admission date may be provided.

NISU two-monthly data summary report, national

NISU report will summarise incident case notifications received during the preceding two-month period in the format below:

SU	gender	age-group	Injury level
		(<15, 15-24, 25-34, 35-44, 45-54, 55-64, 65+)	(C-x, T-x, S-x)

Per cent of missing data should also be reported for each field. Only national rates to be calculated.

NISU six-monthly data summary report, national

Incident cases

NISU report will summarise incident cases admitted during the preceding six-month period by state and SU in the format below:

SU x (gender, age-group, injury level, admissions per month)

Overall, present data on broad causes of injury

Summarise also non-SU admitted cases, by state, gender, age (years) and broad cause of injury.

Per cent of missing data should also be reported for each field. Only national rates to be calculated.

Prevalent cases

NISU report will summarise notifications reported for prevalent cases as below.

Number of people living with SCI in each state

Number of re-admissions, and rehabilitation admissions

NISU annual data summary report, national and state

NISU report will summarise incident cases admitted and notifications reported for prevalent cases during the preceding year by state and SU in the format below:

Incident

Numbers of notifications: SU based, and extra-SU
Age-group, gender distribution, injury level, complete/incomplete

Country of birth, aboriginality

Principal, additional diagnoses
Length of stay and separation mode, by injury level, gender

Summary of when (date/time) injuries occurred, plus broad cause

Prevalent

Number of cases resident in each state, by age-group, gender, injury level
Summarise additions and losses to each state population

Report on notifications for: admissions for rehabilitation, and SU re-admissions

Classify, at national level, prevalence notifications by gender, age-group, and level of injury

Report on marital, occupational status, achieved educational levels
rates of compensation

Mortality

Number of deaths, compared with deaths recorded in previous year (taking note of reporting delays)

Deaths by state

Deaths by broad cause

Survival time for these deaths (date death - date injury)

Appendix VII: Recommended stages of SCI register development

Stage I

To establish the incidence register, it is recommended that the following steps be taken.

- SUs agree to the proposed uniform core data set (specified in Appendix V);
- SUs incorporate the collection and entry of core data items as part of their routine record keeping (see sample reporting tools, Appendix V);
- every two months SUs notify traumatic cases of SCI to NISU (see the incident case notification form, Appendix V);
- NISU manage a national register of incident cases of SCI;
- NISU report back to SUs, on a two monthly basis, summaries of patient admissions, State and national summaries of cases reported semi-annually, and an annual report (specified in Appendix VII);
- a computerised system of registration for incident cases should be developed as part of a more general SCI surveillance computer system. This is further described below.
- SUs inform paediatricians and other clinicians of the surveillance system, and request them to notify NISU of non-SU cases of SCI;
- to aid this process NISU may also examine State Inpatient Statistics Collections to identify non-SU hospitals treating people with SCI, so that these hospitals may be requested to notify SCI cases to SUs;

Stage II

To establish the prevalence register, it is recommended that the following steps be taken.

- A research officer be employed temporarily, to initiate and coordinate the conduct of the SCI census and, through the specification and development of a computer system, establish the prevalence register and its operation.
- The Walsh register be used as a basis for the new prevalence register. As much data as may be transcribed or converted to the new data standard should be updated from the earlier register.
- Admissions to SUs occurring since 1993 be added directly to the new register.

- SCI support groups be invited to become involved in the conduct of a census of traumatic SCI, and that it be organised with the fullest participation of the SCI community.

- A computer system be developed, to manage surveillance data generally. Additional to registration of incident cases, facilities for managing prevalent case mortality and morbidity notification data, and report generation, should also be pursued.

- NISU be invited to operate the prevalence register at the national level.

- A strategy be developed, and tested for a defined area and population.

- The SCI census be carried out at the national level.

- Direct efforts be made to recruit paediatric cases to the register.

- An anonymous random sample of the SCI population be requested for information on their well-being, and that questions be asked on marital status, employment and compensation status.

- SUs monitor additions to the register, by notifying incident cases of SCI to NISU.

- NISU monitor deaths occurring in the prevalent population, by routinely examining the National Death Index.

Stage III

Following establishment of the prevalence register, it is recommended that the long-term well-being of the SCI population be monitored. The following steps should be taken.

- Following the discharge of rehabilitation patients, rehabilitation units routinely (two-monthly) inform SU and NISU of the functional levels attained, and provide updated information on indicators of well-being, using the prevalent case notification form (Appendix V).

- As re-admissions occur, SUs should again provide updated information on indicators of well-being, and these data, using the prevalent case notification form, should be reported to NISU every two months. By computerising this information, SUs may should also directly monitor their bed occupancy rates.

- Similarly, support groups should notify SUs of the long-term well-being of prevalent cases, obtained on occasions of community care provision, and again using the prevalent case notification form. These data can assist support groups in monitoring their levels of service provision.

- A triennial mailed random sample survey of the population be undertaken, in which questions relating to well-being should be asked, in addition to questions relating to issues of topical importance. The input of the SCI community and the support groups into formulating these surveys is especially to be sought.

To monitor the occurrence of mortality, the following recommendations are made.

- SUs and support groups inform NISU of deaths coming to their attention, using the death notification form (Appendix V).

- NISU further monitor, through the National Death Index, deaths occurring in the prevalent population, and inform SUs of these cases.

Stage IV

As the surveillance system becomes operational, the scope of surveillance should be enlarged to include the monitoring of early SCI mortality and the more extensive monitoring of morbidity in the following ways.

- NISU undertakes, through examination of coronial records, monitoring the incidence of SCI in people not surviving to be treated in any clinical facility;

- a more systematic investigation of the occurrence of morbidity in the SCI population be undertaken. Possible approaches include surveying the population for morbidity requiring hospitalisation during the previous year and, with the agreement of the SCI community, providing their ethical requirements can be met, through the linkage of the SCI prevalence register with State Inpatient Statistics Collection data.

- depending on the interest of rehabilitation and support institutions, data collection, particular to these specific phases of SCI within these organisations, may be systematised at the national level, and form part of a more generalised system of SCI surveillance.

Appendix VIII: Preliminary budget

Objective: To establish and maintain a national register of SCI

- Establish the prevalent SCI population
- Develop appropriate software to manage the register

The completion of these stages may be organised as a number of steps, which may be undertaken in two concurrent phases.

The software component of the surveillance system should encompass two aspects: computer programs to manage the central prevalence register, and secondly to manage the peripheral monitoring operations. Organised under the four SCI populations that have been defined, these can be summarised:

Phase 1: Development of computer system

- Finalise agreement on data set, forms, and reports

- Contract computer systems analyst to draw up specifications

- Contract computer programmer to write and implement software

- Determine which SUs require computer hardware, and purchase computers

- Educate SUs in use of the incidence monitoring system, in entering, analysing, and reporting data

- Review software operation at 2 weeks, 2 months, and overall performance of system at 4 months.

Phase 2: Establishment of prevalent register

- Extract all records from Walsh register, and recently admitted SU patients with traumatic SCI

- Compare these cases against the National Death Index, to ensure no-longer living people with SCI are excluded from register

- Conduct focus groups, to involve SCI community in the project, to identify and determine utility of other sources of information, and to determine strategy for conducting census

- Pilot the strategy through a public opinion service

- Use advertising to inform people with SCI, who are unlikely to come into contact with SCI service configuration, of the census

- Initiate census, and manage incoming data, comparing it with already known prevalent cases to prevent double-counting, and to determine final prevalence register

- Use statistical modelling to determine the level of completeness of the register

Costs associated with the above steps

Item	Cost
Research Officer (6 months) Salary + oncosts	$30 000
Computer hardware 4 computers	$12 000
Software development System analysis	$5 000
Programming	$10 000
Professional public opinion research	$8 000
Travel	$5 000
Total	**$70 000**