Clinical Data Linkage in Spinal Cord Injury

By

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A thesis admitted in total fulfilment of the requirements for the degree of

Doctor of Philosophy

October, 2021

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Declaration

This is to certify that

i. The thesis comprises only my original work towards the PhD except where indicated in the *Preface*,

ii. Due acknowledgement of all other material used has been made in the text,

iii. The thesis is less than 100,000 words in length, exclusive of tables, figures, bibliographies and appendices.

Jane Dominique Moon, October, 2021

Acknowledgements

I have been privileged to have experienced tremendous generosity, encouragement and kindness on multiple levels from many as I pursued my endeavour; so thank you...

To my supervisor, Dr. Mary Galea, who rescued me from the problematic initial stages of my PhD studies and helped me to align myself in the Faculty of Medicine. Her kindness was heartfelt and her generosity and patience with editing has been tremendous.

To Megan & Alex with their expertise in the field of clinical data linkage and statistical analysis.

To Graeme & Andrew for igniting interest in the project and inviting me to the world of the spinal cord community. Their energy and optimistic view on patient care have inspired me to continue.

To my family and friends, for love, endurance and understanding over the last eight years. Huge thanks to my husband Kevin, for being a friend and a mentor whom I couldn't do without.

To my son, Benjamin, who has encouraged me to continue and promised me that I would get a 'graduation teddy bear' upon completion.

To my sister, Serena, for having a belief in me and for giving me space to concentrate and for her understanding of my need to be excluded from some family duties.

To my friends, especially Sarah, for weekly walks in the earlier part of the PhD when things were unsettled, to Dorothy for her unconditional support, to Helen for taking me out for regular golf games to calm me down, to John for his advice on articles, and to my dearest friend Reem, for her enduring friendship and multiple pictures of motivation and occasional surprise by post. I couldn't do this without your support. I thank you from the bottom of my heart!

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ACRONYMS AND ABBREVIATIONS

ABS	Australian Bureau of Statistics
ACS	Australian Coding Standards
ADC	Ambulance Data Collections
ADEC	Australian Early Childhood Development Census
ADL	Activities of Daily Living
ADR	Adverse Drug Reactions
AEDC	The Australian Early Development Census
AI	Artificial Intelligence
AIHW	Australian Institute of Health and Welfare
ANDS	Australian National Data Service
ANZICS	Australian New Zealand Intensive Care Unit Society
APACHE	Acute Physiology and Chronic Health Evaluation
APDC	Admitted Patient Data Collection
AR-DRG	Australian Refined Diagnosis Related Group
ASCIR	Australian Spinal Cord Injury Register
ASIA	American Spinal Injury Association
BCLHD	British Columbia Linked Health Database
CCR	Central Cancer Registry
CoDDaC	Controlled Drugs and Data Collection
CDL	Clinical Data Linkage
CDSS	Clinical Decision Support Systems
CHeReL	Centre for Health Research Record
CPOE	Computerised Provider Order Entry
CVD	Cardiovascular disease
CVDL	Centre for Victorian Data Linkage
DHHS	Department of Health and Human Services
DL	Data Linkage
DRG	Diagnosis Related Group
DRP	Drug Related Problems
EDDC	Emergency Department Data Collection
EHR	Electronic Health Record
Febrl	Freely extensible biomedical record linkage
HACC	Home and Community Care
HITH	Hospital In The Home
ICU	Intensive Care Unit
ICD-10AM	International Classification of Diseases, 10th revision, Australian Modification
EHR	Electronic Health Record
FIM	Functional Independence Measure
GP	General Practitioners
HDSS	Health Data Standards and Systems
HIS	Hospital Information Systems

ISNCSCI	International Standard for the Neurological Classification of Spinal Cord Injury
LIS	Laboratory Information Systems
LOS	Length of stay
MCHP	Manitoba Centre for Health Policy
MBS	Medicare Benefit Scheme
MHCSS	Mental Health Community Support Services
NAPLAN	National Assessment Program: Literacy and Numeracy
NCIMS	Notifiable Conditions Information Management System (NCIMS)
NCRIS	National Collaborative Research Infrastructure Strategy
NHDD	National Health Data Dictionary
NHMD	National Health Morbidity Database
NHMRC	National Health and Medical Research Council
NICU	Neonatal Intensive Care Unit
NIH	National Institutes of Health
NISU	National Injury Surveillance Unit
NLI	Neurologic Level of Injury
NMDS	National Minimum Data Set
NWAU	National Weighted Activity Unit
ORLS	Oxford Record Linkage Study
PBS	Pharmaceutical Benefits Scheme
PD	Principal Diagnosis
PDC	Perinatal Data Collection
PDSS	Prescribing Decision Support Systems
PERL	Practical Extraction and Reporting Language
PHRN	Population Health Research Network
PPRL	Privacy Preserving Record Linkage
PRS/2	Patient Reporting System, Version 2
SAIL	Secure Anonymised Information Linkage
SANT	South Australia and Northern Territory
SDLS	Scottish Data Linkage Systems
SCN	Special Care Nursery
SMR	Standardized Mortality Rate
SU	Spinal Unit
TAC	Transport Accident Commission
TDLU	Tasmanian Data Linkage Unit
VAED	Victorian Admitted Episodes Dataset
VCR	Victorian Cancer Registry
VEMD	Victorian Emergency Minimum Dataset
VINAH	Victorian Integrate Non-Admitted Health Dataset
VPDC	Victorian Perinatal data collection
VRMDS	Victorian Radiotherapy Minimum Dataset
VSTORM	Victorian State Trauma Outcomes Registry
VSTS	Victorian State Trauma Systems
WADLS	Western Australia Data Linkage Systems
WEIS	Weighted Equivalent Inlier Separation
WHO	World Health Organization

PUBLICATIONS

There have been 9 publications during the course of the PhD.

Book

Moon, J. and Galea, M. (Eds) (2015). *Improving Health Management through Clinical Decision Support Systems.* Hershey: IGI.

Chapter 1
Overview of Clinical Decision Support Systems in Healthcare (pages 1-27)
Jane Dominique Moon, Mary P. Galea

A Predictive Analytic Model for Maternal Morbidity (pages 108-126)
Edgardo Palza, Jorge Sanchez, Guillermo Mamani, Percy Pacora, Alain Abran, Jane Moon

Chapter 8
Integration of Automation and Clinical Decision Support Systems (pages 165-185)
Ronnel Nallas, Jane Moon

Chapter 15
Strategic Approach towards Clinical Information Security (pages 329-359)
Sangseo Park, Jane Moon

Refereed Journal Papers

Moon, J., Bohensky, M., & Galea M. (2016). Challenges in Clinical Data Linkage in Australia: Perspective from Spinal Cord Injury. *International Journal of Big Data and Analytics in Healthcare (IJBDAH)*. Issue1, Jan-June, pp 18-28.

Book Chapters

Moon, J., & Bohensky, M. (2014). Using Clinical Data Linkage for Health Care – What are the concerns? In Wang and Li (Eds). *Big Data Analytics in Bioinformatics and Healthcare.* Hershey: IGI. Chapter 17, pp 392-405.

Moon, J. (2015). Overview of CDSS in health. In Moon and Galea (Eds). *Improving Health through Clinical Decision Support Systems.* Hershey: IGI. Chapter 1, pp 1-27.

Moon, J., & Park, S. (2015). Strategic Approach towards Clinical Information Security Systems. In Moon and Galea (Eds). *Improving Health Through Clinical Decision Support Systems*. Hershey: IGI. Chapter 15, pp 339-359.

Nallas, R., & **Moon, J.** (2015). Integration of Automation and Clinical Decision Support Systems. In Moon and Galea (Eds). *Improving health through clinical decision support systems*. Hershey: IGI. Chapter 8, pp 165-185.

Edgardo, P., Jorge, S., Guillermo, M., Percy, P., Alain, A., & **Moon, J**. (2015). A Predictive Analytic Model for Maternal Morbidity. In Moon and Galea (Eds). *Improving Health Management through Clinical Decision Support Systems*. Hershey: IGI. Chapter 5, pp 108-126.

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Moon, J., Galea, M, Bohensky, M, Hart, G., & Nunn, A. A descriptive retrospective analysis of linked emergency, admission and ICU datasets at the Austin Health from 1998-2015, abstract presented at ANZSCOS, Perth, 2015

ABSTRACT

Introduction

This is the first Australian longitudinal retrospective study on the patients with traumatic Spinal Cord Injury (SCI), over a 14-year period, showing the trends of disease as well as health service utilization. This study involved linking Intensive Care Unit (ICU) datasets with Victorian Admitted Episodes Dataset (VAED) and Victorian Emergency Minimum Dataset (VEMD) from three major hospitals to work out determinants for disability, as well as co-morbidities.

From the collected data, the study provides frameworks for chronic disease such as SCI and developed a prototype that can be used to bring the information together to be utilized by clinicians, patients and carers to improve health outcomes.

Methods

Health administrative datasets with the International Classification of Diseases, 10th revision, Australian Modification (ICD-10-AM) were used to conduct a pilot data linkage study using a unique identifier. A deterministic linkage method was used to link internal datasets from each of three major hospitals to build patient disease profiles and identify comorbidities. An extended Elixhauser comorbidity index (ECI) was used to study risk factors and comorbidities.

Results

The study identified a lack of coordination between clinical, administrative and statutory data custodians, and issues with coding quality. From the linked datasets from three major hospitals (Alfred Hospital, Royal Melbourne Hospital and Austin Hospital) data on almost 2,629 patients were extracted. The female: male ratio in this cohort was 1:2.9 and the largest proportion of patients was aged between 16 and 30 years. An increase in female admissions was apparent in the last decade. Sixty-six percent of readmissions were for patients from the Melbourne metropolitan area, with much lower proportions in the Gippsland and Hume regions.

The three most frequent principal diagnoses were functional level of cervical spinal cord injury (C1-C8), concussion and oedema of thoracic spinal cord and concussion and oedema of cervical spinal cord.

The main reasons for readmission were urinary tract infection (UTI), pressure ulcer, mental disorders and respiratory infections.

The study of risk factors (alcohol, tobacco and illicit drugs) showed a significant association with overall length of stay in ICU and that males had twice the risk of death than females.

Using the linked datasets as backend, a prototype of clinical decision support system (CDSS) was developed. This has scalability and can be improved with the latest technologies such as an 'alert system', as well as built-in artificial intelligence (AI) such as an Artificial Neural Network, which can assist clinicians, patients and carers.

Conclusion

This is the first longitudinal study of SCI, following the e-journey of patients with SCI over 14 years in three major hospitals in Victoria. The lack of coordination between clinical, administrative and statutory data custodians, and issues with coding quality have implications for resource allocation, decision making and planning by health administrators and clinicians.

Although the total number of people with spinal cord injury is small, they have prolonged health utilization. This Clinical Data Linkage study has provided unique information about these patients, including the enormous number of readmissions, the reasons for readmission, the exact cost of care at the major Victorian hospitals rather than estimates, and the area of the residence of patients where ongoing care is needed.

Ultimately, stratified patient profiles can be used as a backbone for eHealth and a as framework for clinical decision support systems that are known to support self-efficacy for patients with chronic conditions and to improve health outcomes. They may also be used to build a conceptual model for other chronic conditions that have a high number of medical interventions.

Chapter 1

Introduction

CHAPTER 1 INTRODUCTION

Spinal Cord Injury (SCI) is a traumatic condition in which most survivors have a high dependency on medical and social support over extended periods of time (Rabinstein, 2018). The average life span after injury is around 40 years. The latest review suggests there has been a significant increase in the incidence of SCI in people aged over 40 years in Australia (AIHW, 2021).

Around a third of people with traumatic SCI will be hospitalized each year, placing a large burden on health expenditure as well as on quality of life (Jaglal et al., 2009). People with SCI consistently return to hospital for treatment for complications such as urinary tract infections, pneumonia and a range of other conditions (Guilcher et al., 2013; VNI, 2011).

Due to the seriousness of their injury and comorbidities, patients with SCI require high levels of medical intervention. However, some aspects of their medical history are not always current, reliable and available to the appropriate health professional throughout their life. Even though Australia is one of the leading countries in the use of Clinical Data Linkage (CDL), very little has been done in linking information in the field of SCI. CDL is a technique where data from different sources relating to the same person can be linked to ensure that it will be available to the right people for the right use and at the right time. However, current CDL in Victoria does not extend to people with SCI.

The studies reported in this thesis were designed to map the disease pattern of patients with SCI, a condition which has heterogeneous data custodians. Trying to link patient records that reside in an array of networks and to bring them together efficiently, and hence to make them readily available to treating clinicians as well as carers and patients themselves, requires an understanding of health systems.

According to Robson (2002), research questions drive the types of methods for a study. The work described in this thesis is located at the intersection of the domains of medicine and information systems. The information systems field has developed and elaborated theories and methods for studying information technology (IT) in social and organizational contexts (Layman & Watzlaf, 2009). The research approaches are often complementary and can have a synergistic effect, as a well-designed interface has been shown to improve health outcomes in chronic disease (Karmel, Lloyd, & Anderson, 2008).

Health Informatics (HI) and Medical Informatics (MI) are terms used synonymously. Both HI and MI were developed as research fields focused on realizing the potential to use computer and information technologies in health care and have produced a valuable body of knowledge in healthcare IT (Shortliffe & Blois, 2001; Shortliffe & Cimino, 2006).

Given the exploratory nature and 'complexity of the phenomena' in this study (Östlund et al., 2011), the principal methods of investigation chosen include quantitative approaches (Cresswell, 2003; Newman, 2011; Östlund et al., 2011).

1.1 Trauma Centres

The incidence of major trauma in Australia declined significantly from the middle of the 1970s to the 1990s after the introduction of mandatory seat belts while driving (McDermott and Hough, 1979; Mullins, 1999) and wearing helmets, random alcohol blood testing and speed cameras have substantially reduced road trauma. The introduction of a Level 1 Trauma Centre was found to result in fewer preventable deaths (Cooper et al., 1998). The Victorian State Government established a taskforce to review trauma and emergency services: 'the right patients to the right hospital in the shortest time" (Atkin et al., 2005).

As a result, the Victorian State Trauma System (VSTS) was established in 2000, jointly funded by the Victorian Government and the Transport Accident Commission, with its main role being to facilitate the management and treatment of major trauma patients in Victoria (VSTS, 2021). The success of the system relies on the quality of data collection and analysis.

A statewide major trauma database, the Victorian State Trauma Systems Registry (VSTSR) was established, which collects data from 138 health services to monitor quality of service and patient survival over time, and to compare outcomes between patient groups (VSTSR, 2021). This information is used to monitor and assess each component of the Victorian State Trauma System to facilitate further enhancement. While the service is stable, there are still challenges in delivering quality services to the booming Victorian population, which is increasing at a rate of 100,000 per year, through proper governance (VSTORM, 2021).

The annual report of the VSTR shows that in the period 2014-2015, SCI accounted for 7% of total admissions (VSTR, 2021). These patients are transferred to the Victorian Spinal Cord Service, a specialized centre for spinal cord injuries based at Austin Health (Austin, 2021).

1.1.1 Austin Health

The Victorian Spinal Cord Service at Austin Health is one of six specialist services in Australia. It provides services for acute management and rehabilitation for people with traumatic and non-traumatic spinal cord injuries from Victoria, Tasmania and the Riverina region of NSW. It is part of Victoria's State Trauma System (Austin, 2021) and it provides definitive services to all patients with major trauma resulting in spinal cord injury in Victoria (VSTS, 2021). Austin Health serves as a funnel for patients, first admitted to either Alfred Health or Melbourne Health, who require specialist management, as Austin Health is the only Centre in Victoria which provides specialist rehabilitation for patients with traumatic SCI (Austin, 2021).

1.1.2 Alfred Health

The Alfred Hospital is one of two major adult Trauma centres in Melbourne, the other being the Royal Melbourne Hospital. The local catchment area includes Bayside, Stonington, Glen Eira, Kingston, Port Phillip and Melbourne. Its helipad facilities, which were set up in 2012, bring patients from the accident directly to the hospital (Alfred Health, 2021).

1.1.3 Royal Melbourne Hospital

The Royal Melbourne Hospital (RMH) is the second major adult trauma centre in Victoria, serving the inner Melbourne districts. It is an acute tertiary referral centre, with one of the biggest Emergency services, including helipad facilities for urgent cases that need to be airlifted from regional areas to reduce mortality (RMH, 2021). The helicopter service was reduced at the Royal Melbourne Hospital in 2013- 2014 due to construction (VSTS, 2021).

1.2 Context of the research

From the perspective of medicine, the clinical features of Spinal Cord Injury (SCI) and the characteristics of the acute and chronic stages of SCI will be explained, as well as its impact on health expenditure as a chronic disease, as this will help us to understand the complexities of medical intervention. SCI has been chosen for this study as it enables the conceptualization of general models of care applicable also to other chronic illnesses. SCI is complex in its own right but detailed profiles of patients with SCI have not yet been captured by individual datasets from trauma registries.

From the perspective of methodology, the research uses the statistical method of Clinical Data Linkage (CDL) to integrate disparate health data sets belonging to patients with SCI. The success of CDL depends on the types of statistical methods and data quality. Techniques involved in CDL and data quality will be explored and recommendations for the best methods will be provided in Chapter 3.

Analyzing linked datasets over a period of 14 years from three major trauma centres in Victoria will provide powerful resources for investigating the causes of co-morbidities of people with SCI. This patient profile will be used to develop a conceptual model for management of SCI and other chronic conditions with high medical interventions.

1.3 Contribution of this thesis

The aim of this thesis is to bridge the gap in health information about SCI by integrating disparate datasets using CDL methods and analyzing them to provide a deeper understanding of disease patterns of patients with SCI. Use of CDL is powerful, as this approach can provide information from a large population, a more holistic approach than merely a snapshot of information. Most of the work on CDL has been for the purpose of research and statistical analyses, but to the best knowledge of the researcher, this is the first longitudinal study of disease mapping in patients with SCI in Australia. As will be shown in Chapters 5 and 6, this has yielded novel information that has not been captured in reports published to date.

It is hoped that the thesis will make a contribution to both practice and theory, in the following ways:

1.3.1 Contribution to Theory

A framework for prediction of health information flow for chronic disease will be constructed from the study of multiple databases. This framework can also be applied in other types of chronic diseases and can be used for tracing health information flow and data linkage.

The conceptual model for management of SCI will be deduced from the retrospective time series analysis in Chapters 5 and 6, which can be used for prediction and planning of health economic/morbidity modelling to maximize individual patient, physician and community benefit. The proposed model could potentially be used for scheduling for investigations and interventions based on risk profiles.

1.3.2 Contribution to Practice

The thesis will contribute to practice by identifying various health data custodians and linking data that can be available for patient care. This type of research involves the political, technological, privacy and ethical challenges of clinical data linkage. However, linking these datasets fills a gap in patient records. The individualized risk profiling from the retrospective analysis study will provide guidance to physicians and individuals regarding disease prevention strategies.

When successfully implemented, CDL can have a large impact on the efficiency of hospital admissions and foster a holistic approach to rehabilitation, as it can provide a full picture of long-term treatments and of medications, social dependencies, and administrative data, and provide clinical support for allied health professionals and primary health providers. CDL can reduce duplication of tests and of treatment, make it easier to follow medications, and facilitate better prediction of disease states and their prevention and treatment.

1.4 Gaps in knowledge

Patients with SCI impose a heavy burden on health expenditure through their life span and they rely heavily on support of doctors, carers, social workers and allied health services. Secondary complications are very high, leading to multiple hospital readmissions. The current information systems in Australia are not mobilized to bring all the necessary information together with respect to SCI.

There is a gap in knowledge of the high intervention needs of patients with SCI, especially with respect to the reasons for readmission. While common complications associated with SCI are well-known and reported, understanding of the risk factors and comorbidities of patients with SCI is limited. Moreover, while there is some evidence of resource utilization by patients with SCI, this information is scattered. Many patients have prolonged need of medical intervention post-discharge from the initial admission, yet there is a lack of follow-up studies post- discharge. Thus, the full picture of the medical journey of patients with SCI is not currently available.

1.5 The Research Questions

The guiding question for this research are:

1. How can integrated health information systems improve health outcomes for patients with SCI? What is the framework for understanding the health information cycle for chronic diseases?

2. What is the disease pattern of SCI, what are the risk factors and how could this information support clinicians?

3. How can a conceptual model be built to help manage patients with SCI for better health outcomes, and can this be transferred to technology-based software such as clinical decision support systems (CDSS) to support the clinicians?

These questions can be divided into the following sub-questions:

1: Clinical Information Flows and Clinical Data Linkages: Clinical Data Linkage:

- What kind of health information is generated about patients with SCI, and which aspects of the datasets should be linked and integrated?
- What is the best framework for the health information cycle for chronic diseases?

2: Individual Patient Profile, retrospective time series analysis:

- What is the pattern of disease and reasons for readmissions identified from the data linkage studies?
- What risk profiles can be identified in patients with SCI?
- What are the risk factors, comorbidities and health utilization of patients with SCI?

3: Conceptual Model for the management of SCI:

- What are key characteristics of patients with SCI?
- What models have been used in other areas of research?
- Can a conceptual model be built to help manage SCI for better health outcomes?
- Does this model have potential for translation to other chronic diseases which require high use of medical intervention?
- Can information about SCI be transferred into a technology-based app, a clinical decision support system (CDSS) which can assist clinicians, patients and carers?

1.6 The structure of this thesis

In Chapter 2, an extensive review of epidemiology of SCI is presented. This includes background of the classification and the incidence and prevalence of SCI. The pathology and classification of SCI, and Australian health information, are discussed.

Chapter 3 presents an extensive literature review of clinical data linkage with prevailing international and Australian scenarios. This section identifies the stakeholders, and how the information is collected and utilized. Multiple data custodians involved in the collection of health information from patients with SCI are identified. The significance of data quality, as well as various data linkage methods, is explored.

Chapter 4 provides details of the methods used to draw together the three areas of research methodology. The basis for the major part of this thesis, time series analysis, is explored. The Results reported in the subsequent Chapters are illustrated in the diagram below:

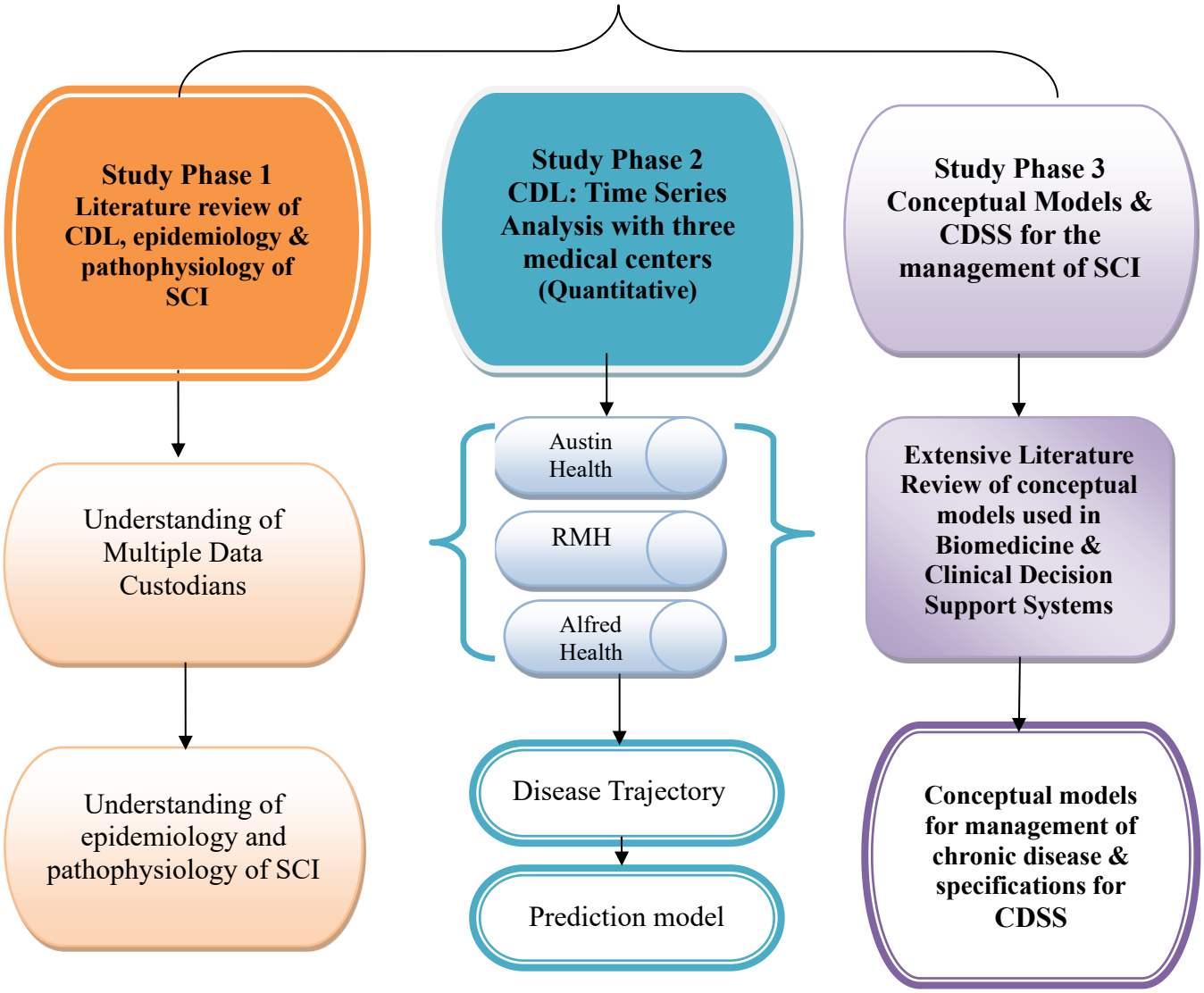


Figure 1: Flowchart of study methods

This research required ethics approval from four different institutions: The University of Melbourne, Austin Health, Alfred Health and Melbourne Health (Appendix: Ethics: 1A, 1B, 1C, 1D).

Chapter 5 presents the results of a pilot study of clinical data linkage and time series analysis of three internal databases within Austin Health from mid-1998 to mid-2008, the site of the specialised centre for SCI in Victoria.

Chapter 6 presents the major study of the thesis. This Chapter provides a time series analysis of SCI from clinical data linkage of nine databases across three major hospitals. The results include data about patients with SCI over a period of 14 years, from which patient disease profiles as well as risk factors and comorbidities were extracted.

In Chapter 7, a conceptual model for conditions such as SCI that require a high degree of medical intervention is described (Study Phase 3). This tool could be translated to other chronic medical conditions, such as liver disease or kidney disease, that require frequent medical services. An historical overview of Clinical Decision Support Systems (CDSS) is provided, with current best practices internationally and in Australia and how this can be applied in chronic disease. A framework for chronic disease is provided and a prototype of a CDSS for SCI is provided.

Chapter 8 provides an overall discussion of the findings of this thesis. It includes suggestions for further research and recommendations for further development of the conceptual prototype, as well as technology based CDSS, indicating the broad potential that this tool has as an application for other chronic diseases.

Chapter 2

Spinal Cord Injury: Prevalence and Pathophysiology

2 PREVALENCE AND PATHOPHYSIOLOGY

2.1 Introduction

This chapter outlines the prevalence and incidence of spinal cord injury (SCI) globally and in Australia. In addition, the pathophysiology of SCI will be presented with matching ICD-10-AM codes to indicate background, common risk factors, comorbidities and health impacts of SCI as a chronic disease.

The "incidence rates reflect the level of control of SCI and the possible need for improved prevention, whereas the prevalence rates have an impact on health care and on social and personal resources" (Wyndaele and Wyndaele, 2006: p523). An accurate estimate of both prevalence and incidence is fundamental to developing preventable strategies, planning health services and providing social services.

The actual pathophysiology of SCI is complicated, and understanding functions related to the spinal cord is essential for management of the condition. Medical treatment and length of treatment vary depending on the types of injury, and rely on accurate assessment of the injury. The American Spinal Injury Association (ASIA) impairment scale, which is used to classify and predict the expected functional outcome for SCI, will be discussed in detail, as this affects management and health outcomes of patients.

SCI can be divided into traumatic spinal cord injury (TSCI) due to car accidents, severe falls and sporting accidents, and non-traumatic spinal cord injury (NTSCI). NTSCI can occur due to spinal bifida from birth, spinal cord compression resulting from spinal degeneration or tumour, or stroke. Cord syndromes that affect specific parts of the spinal cord can result from both NTSCI and TSCI, and can lead to significant physical, psychological and socioeconomic burden on the sufferer, the family and the health system worldwide (Bickenbach et al., 2013). This thesis will focus on TSCI.

2.2 Global prevalence and incidence of TSCI

It is difficult to estimate the exact prevalence of TSCI in the world, as most systematic reviews have come from high-income countries such as the USA, Canada and Australia. Only a small proportion of published papers are from low-income countries, where the data reported is based on regions, provinces or specific hospitals rather than national registries, making it difficult to estimate exact figures worldwide.

Meta-analysis of articles shows a large variation in global prevalence and incidence of SCI worldwide. This is due to the different methodologies that have been used to derive the statistics. Caution is required in comparing reports; for example, some articles report data on adults only, while other reports include paediatric and mortality rates (Cripps et al., 2011) and many countries do not have national registries to capture all cases (Noonan et al., 2012). The lack of consistency in reporting makes it difficult to determine the true incidence and prevalence of SCI (Cripps et al 2011).

2.2.1 Global prevalence TSCI

The most extensive study on global prevalence of SCI comes from Furlan et al., who reported 236 to 1298 cases per million based on all published papers over a period of 62 years (1950-2012) (Furlan et al., 2013). This study supersedes an earlier study by Wyndaele and Wyndaele reporting 223-755 cases per million over the period 1995-2008 (Wyndaele & Wyndaele, 2006). South and South-East Asian cases were estimated to be 236-1009 cases per million based on the study by Cripps et al. over the same period (1995-2008) (Cripps et al., 2011).

There is a large regional variation in prevalence. The highest prevalence was noted in North America, at 906 cases per million (Lee et al., 2014), and in another report at 721-1009 cases per million (Cripps et al., 2011). Country-based comparisons also show significant variation: France, at 250 cases per million (Lee et al., 2014), Finland (280 per million) and Iceland (316 per million) were reported (Singh et al, 2014).

2.2.2 Global Incidence of TSCI

Global incidence of TSCI also shows a large variation. Thirteen to 163.4 cases per million were reported in the latest study by Kang et al. (2018). Similar findings of 3.6 to 195 cases per million were reported by Masetti & Stein (2018), a marked increase from earlier reports of 12.1 to 57.8 cases per million reported by van den Berg et al. (2010), 23 cases per million by Lee et al. (2014) and 8 to 246 cases per million by Furlan et al. (2013).

Two studies reported discernable differences between high- and low-income countries, where the incidence of SCI in high-income countries ranged from 3.6 to 195.4 cases per million in one study (Jazayeri et al., 2015) to 13.1 to 163.45 in the latest study (Kang et al., 2018). Wider variation exists in low-income countries, between 13.0 and 220.0 cases per million (Kang et al., 2018), but there is a lack of reports of TSCI within African and Asian countries. In another review, the

incidence of TSCI was higher in low- to middle-income countries than in high-income countries due to lack of infrastructure and safety features (Kumar et al., 2018).
Country-based comparisons show significant variation in incidence of TSCI. Most reports are from high-income countries: an incidence of 38.4 cases to 40 cases per million was reported for North America (Massetti & Stein, 2018) compared to 13 cases per million for The Netherlands (Bickenbach, et al., 2013) and 18 cases per million in Switzerland (Chamberlain et al., 2015). In Canada, the incidence of TSCI has been reported as 41 cases per million (Noonan et al., 2012).

In Asia, the incidence of SCI in high-income countries such as Japan and Taiwan are well documented, but little is known about other Asian countries. The incidence in Japan is reported as 40.2 cases per million and in Taiwan 18.8 cases per million. The incidence of SCI in Vietnam and Thailand is considered to be underestimated, as neither country has a national registry to accurately record cases (Cripps et al., 2011).

A study of the Mena region (Turkey, Iran, Saudi Arabia, Egypt, Kuwait, Jordan and Qatar) showed that the incidence of SCI ranged from 7.8 cases per million in Kuwait to 72.45 cases per million in Iran, with the average estimated annual incidence in the Mena region at 23.24 per million (Elshahidi et al., 2018).

There are very few reports on Sub-Saharan African areas. Most reports were based on region and hospital admissions from 1990-2010, where 496 patients were treated at the University Hospital in Nigeria, 24 patients were treated in Sierra Leone and 136 patients were treated in Zimbabwe for TSCI (Draulan et al., 2011).

In Oceania, most reports are from Australia and New Zealand. Annual incidence rates varied significantly between regions, ranging from 10 cases per million in Fiji to 49.1 cases per million in New Zealand (Singh et al., 2014). However, the latest published papers based on country show that there was an average of 22 cases per million in New Zealand (2007-2016), a lot lower than in previous studies (Mitchell et al., 2020).

2.3 Risk Factors of TSCI

The major cause SCI in most countries is Motor Vehicle Accident (MVA). The peak age of males involved in MVA is less than 30 years, and males are at higher risk of SCI than females (van den Berg et al., 2010, Draulan et al., 2011; Kang et al., 2018, Elshahidi et al., 2018). A change in trend is showing in the USA, where the average age for MVA has shifted from 28.7 years (1973-1979) to 40.2 years (2005-2009) and the leading cause of SCI also shifted from MVA to falls (Selvarajah et al., 2014). Similar findings were reported in Japan, where falls were the leading cause of TSCI (Miyakoshi et al., 2020).

The incidence of violence and self-harm causing TSCI was highest in North America (15%), compared to Western Europe (6%) and Australia (3%) (O'Connor, 2005). Falls from either elevation or on the ground were the major cause of TSCI in elderly groups in high- income countries such as Japan (42%), Western Europe (37%), Australia (29%) and North America (20%) (Singh et al., 2014). This trend could be due to a higher proportion of older populations in Japan and Western Europe than in Australia and North America (the population >60 years is 33%, 23.9%, 18.9% and 18% respectively) (Cripps et al., 2008; Cripps, 2011). This trend is expected to grow in line with aging populations (Hamid et al., 2018).

2.4 Prevalence and incidence of TSCI in Australia

The latest incidence of TSCI reported in Australia from the National Spinal Cord Injury Registry in 2020 is 11.1 per million population (227 patients) aged 15 years and over (period 2016-2017) (Tovell, 2020). This is a reduction of 26% since 2007 where 15-17 cases per million was reported (Cripps, 2011; New & Sundararajan, 2008) (period 2007-2008), and a 24% (14.5 cases per million) reduction since 1998-1999 (O'Connor, 2002). Tovell (2020) reports the 3-year standardised rates of TSCI, with the highest incidence in Western Australia (17.8 cases per million) and the lowest in Tasmania (6.2 cases per million).

In Australia all patients with SCI are registered with a national body, the Australian Spinal Cord Injury Register (ASCIR). The register includes injuries that occur in Australia and to Australian residents from overseas who have been treated in a spinal unit in Australia. ASCIR was established in 1995 by the National Injury Surveillance Unit (NISU), a collaborating centre of the Australian Institute of Health and Welfare (AIHW), in conjunction with the seven spinal units (SU) in public hospitals across Australia specializing in acute management and rehabilitation of people with SCI.

Patients from States and Territories which have no spinal units (Tasmania, the Northern Territory, and the Australian Capital Territory) are sent to the nearest available spinal unit for treatment. All ASCIR captured data are reported biennially through AIHW and there has been a total of 18 reports since the inception of ASCIR (Tovell, 2020).

Each year approximately 300-400 cases of TSCI are registered with the national register, but this number is an underestimation, as it does not include patients who are not registered with spinal units or those who have not consented to be registered. Nor does it include people under 15 years of age. People under 15 years are treated in specialist paediatric hospitals and are not reported to the register. In addition, the register does not capture patients who are discharged from the acute hospital directly into the community (Tovell, 2020; New et al., 2015).

Caution is also needed when looking at these reports as some jurisdictions that have low cases of TSCI report triennially rather than biennially. For instance, no cases were reported from the Australian Capital Territory for 2006-2007. Only 19 cases were reported from Tasmania and 12 cases from the Northern Territory over three years. New et al. reported an incidence of TSCI of 21.0 to 32.3 per million in Australia as at 30 June 2011, which is substantially higher than reports by AIHW at the same time (2011) but their report has used datasets from the National Hospital Morbidity Database, which contains data on both adults and children as well as patients who died at the scene of the accident (New et al., 2015).

2.4.1 Demographics

The majority of TSCI cases (80%) reported in 2016-2017 were males (n=176) compared to females (n=40) in the same period. The highest number of cases was in the age group of 45-54 years in the latest report (2016-2017) followed by cases aged 15-24 and 25-34. Across 22 years of ASCIR data, the incidence rates were consistently higher for males than for females aged 15 and over (Tovell, 2020).

The age-standard trends in TSCI from 1995-2017 are shown in Figure 2.1.

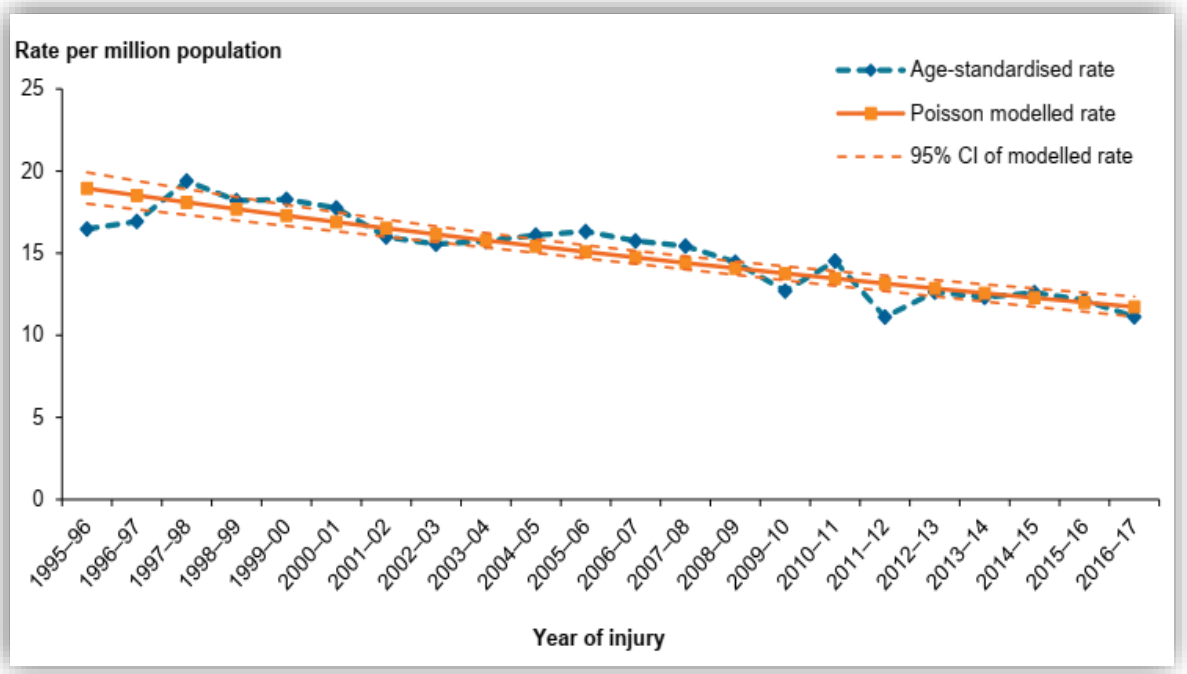


Figure 2-1 Trends in TSCI by year of injury, 1995–96 to 2016–17

Source: (Tovell, 2020) with permission.

It can be seen from the graph that the incidence rate of TSCI at age 15 and over has declined since 1995–96 by an average of 2.3% per year (95% CI –1.8% to –2.7%). The group with the greatest incidence of TSCI was the 15-24 age range (1998-1999). With increasing age, declining incidence is noticeable. The leading causes of TSCI for males were transport-related injuries (49 cases; 27%) while the leading cause of injury for females was falls (16 cases; 36%).

Lau et al. (2014) studied the epidemiology of cervical spinal cord injury at the Victorian Spinal Cord Injury Service from 2000 to 2009 (n=206). They found that the male to female ratio was 4:1 with a mean age of 36 years (age range 12-90 years). Their findings suggest that males most commonly experience cervical spinal cord injury in their thirties (31.3%), whereas women showed a peak in their seventies (18.9%), with a second peak in the thirties (16.2%) (Lau et al., 2014).
While the occurrence of TSCI is increasing, its severity is decreasing as a result of better emergency and medical care (AIHW, 2020). Middleton et al. (2012) studied the mortality and life expectancy of TSCI in New South Wales in the 50 years from 1955 to 2006. Their study showed that mortality rate has a direct relationship with neurological impairment. The mortality rate in the first year was 8.2% for tetraplegia and 4.1% for paraplegia. Among first year survivors, the overall survival rate was 47% for tetraplegia and 62% for paraplegia (Middleton et al., 2012).

2.5 Paediatric SCI

While paediatric SCI is not within the scope of this thesis, understanding the epidemiology of paediatric SCI is important for future planning of health services, given that the life span of people with SCI is increasing.

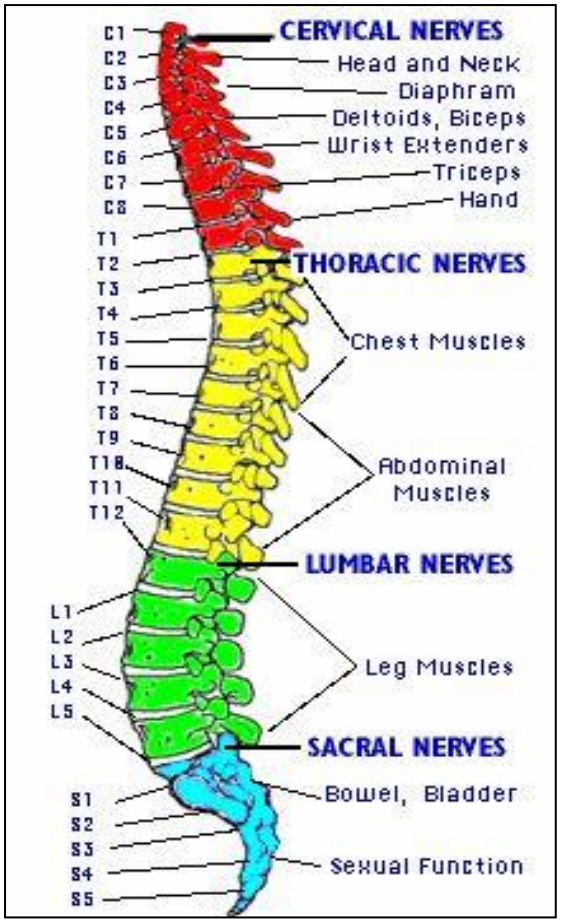
Globally the estimated incidence of paediatric TSCI is 24 cases per million. A higher incidence of serious injuries is reported in black adolescents. Motor vehicle accident seems to be the major cause of TSCI for this age group. However, a decrease in the trend is noted in recent years due to improved vehicle safety and traffic regulations (Hamid et al., 2018).

There have been three published papers on paediatric SCI in Australia, but only one paper dealt with TSCI. Lystad et al. (2020) studied the incidence and cost of hospitalisation for TSCI among Australian children (≤16 years) over a 10-year period (2002-2012) using linked hospital and mortality data. The review found the average annual hospitalization rate was 9.34 per 100,000 population and noted an annual percentage change of 1.2%. An increase in hospitalization was noted for spinal dislocations, sprains and strains of 3.0% for males and 1.7% for female children. The majority of hospitalisation occurred in males aged 11 to 16 years (61.1%). The most frequent causes of injury for all children were falls (40.9%) and road trauma (23.8%). Equestrian spinal injuries were common in females (10.8%). For all children, injuries to the cervical spinal cord were most frequent (52.3%). Almost half the total injuries to children were serious (45.8%), and the mortality rate within 30 days of admission was 14 deaths (0.3%). Paediatric TSCI is strongly associated with mortality and morbidity, creating a burden on the health economy. A targeted strategy to reduce injury has been recommended (Lystad et al., 2020).

2.6 Pathophysiology of SCI

The spinal cord is like the body's switchboard. It carries messages from the brain to virtually everywhere else in the body. Hence when any part of the spinal cord is damaged, the ability for the brain to receive sensory signals or move the body is diminished. Most SCI survivors have some mobility impairments and many are paralyzed. The spine is divided into four broad sections known as levels. In order, from the top to the bottom of the spine, these are the cervical, thoracic, lumbar and sacral levels. The higher the level of injury, the greater will be the dependency on prolonged medical and social rehabilitation (Sarhan, 2012).

The level of the spine at which an injury occurs will indicate which part of the body will be affected. Figure 2.2 shows the four spinal levels, accompanied by a table describing the effects associated with injuries to each level (Fehlings, 2013; Lin, et al., 2003).



Injury site	Condition
C-1 - C-4	Often on ventilation for breathing, with pacemaker.
C-5	Shoulder and biceps movement but no wrist movement.
C-6	Wrist but no hand movement.
C-7 - C-8	Can straighten arms but little dexterity with hands and fingers.
T1 - T-8	Control of hands but poor trunk control.
T-9 - T-12	Good trunk control and good abdominal muscle control.
L-1 - L-5	Paralysis of lower extremities.
S-1 - S-5	Decreased control of bowel and bladder

Figure 2-2 Diagram of the spine showing the four nerve levels (SCI)
Source: (Fehlings, 2013); summary of table drawn from Kim, et al. (2008) with permission.

The pathophysiology of SCI is very complex in that it involves diverse biochemical and physiological changes that occur in the injured spinal cord. A considerable effort has been made by researchers in the last decade to unravel the underlying cellular and molecular mechanisms of tissue degeneration and repair in the injured spinal cord (Dyck & Karimi-Abdolrezaee, 2019). However, apart from research on repair of the spinal cord, more research remains to be done to reduce the causes of accidents, and improve on treatments, rehabilitation and adaption after the injury.

2.6.1 Classification of SCI

The functional outcome of SCI varies depending on several factors. The spinal cord is a bundle of nerve fibers and tissues intricately interwoven to make connections to the body. Damage to any

part of the spinal cord can have an impact on sensory, motor and reflex abilities if the brain is unable to send information beyond the location of the injury. Each SCI is unique and patients with the same level of injury may have a very different presentation, as the injury can be very complex.

The International Standard for the Neurological Classification of Spinal Cord Injury (ISNCSCI) is standardised method for assessment of SCI that is now used worldwide to improve communication across different medical specialties, like a universal language. The American Spinal Injuries Association (ASIA) Impairment Scale (AIS) is used to classify the severity of injury. The ISNCSCI examination is done by physicians and physiotherapists. It enables a determination of the neurological level of SCI (tetraplegia or paraplegia), the extent of injury and the resulting degree of impairment. This is performed at the initial admission and repeated before and after rehabilitation. For the assessment to be done correctly, patients have to be conscious, as the test involves patient cooperation, and limbs immobilized in plaster cannot be assessed.

The assessment involves testing the strength of key muscles in the limbs that are representative of specific spinal segments. Two aspects of sensation are evaluated: light touch and pinprick. In addition, the sacral segments are assessed by examining perineal sensation and voluntary anal contraction. The assessment has three components (Kirshblum et al., 2011):

1. Evaluation of motor function: grades and score for muscle strength and movement.
2. Evaluation of sensation: grades and score for light touch and pinprick feelings.
3. Grading of injury severity using the ASIA impairment scale.

The Neurological Level of Injury (NLI) refers to the most distal level where both motor and sensory function is intact. Sensory and motor function may be different on each side, but a single NLI is usually used to classify the patient. Figure 2.3 shows the ISNCSCI chart which is used to

assess patients. As can be seen, it is a detailed assessment of motor and sensory functions, NLI and AIS.

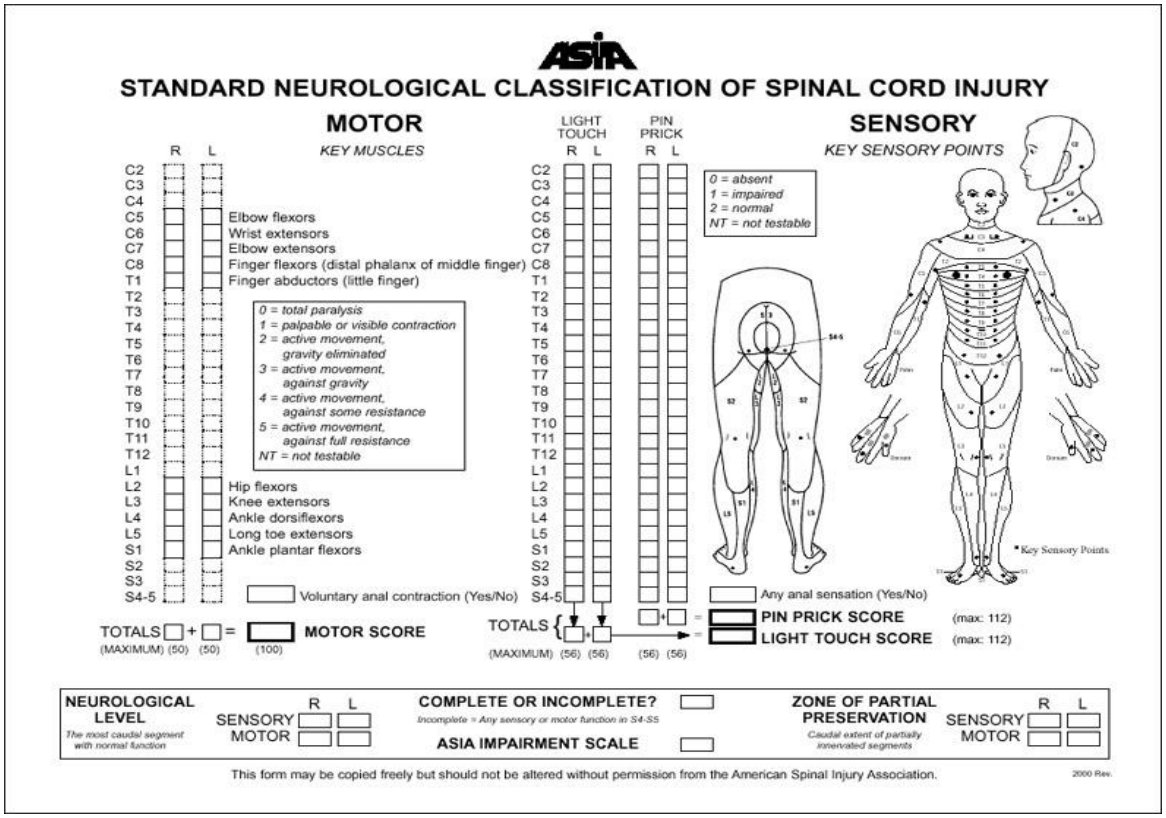


Figure. 2.3 ISNCSCI Chart Source: http://www.ASIA-spinalinjury.org

The AIS has five levels, grade A indicating the most severe injury and grade E indicating no neurological deficit (Kirshblum et al., 2011; Ahuja et al., 2017) (Table 2.1).

Table 2-1 AIS levels

Grade	Effect
Grade A (Complete)	No sensory or motor function preserved below the NLI including absent sacral segments S4-S5. (i.e., No voluntary anal contraction, no great toe flexion, and no perineal, genital, anal pinprick or light touch sensation)
Grade B (Incomplete)	Sensory but no motor function preserved in the sacral segments (light touch or pinprick at S4-S5 or deep anal pressure). No motor function is present more than three levels below the affected neurological level, on either side of the body.
Grade C (Incomplete)	There is voluntary anal contraction and sparing of motor function. Motor function is preserved below the neurological level (including the distal sacral segment), and greater than half of the key muscles (elbow flexors, extensors, write extensors, finger flexors and abductors, hip flexors, knee extensors, ankle dorsiflexors, long toe extensors and ankle plantar flexors) below the NLI have a muscle grade of less than 3.
Grade D (Incomplete)	Motor function is preserved below the neurological level, and half or more of the key muscles below the NLI have a muscle grade greater than or equal to 3.
Grade E (Complete)	Neurologically intact patients. Sensory and motor function is normal.

Apart from the basic classification of SCI, there are many syndromes of incomplete SCI, including central cord syndrome, Brown-Séquard syndrome, anterior cord syndrome, and posterior cord syndrome, which indicate damage to specific parts of the spinal cord (see 2.6.3).

Correct assessment of neurological and functional impairment is important for health policy. For instance, AIS grade D patients who require a wheelchair for daily activities can have an estimated 75% normal life expectancy whereas patients who do not need a wheelchair and catheterization can have a higher life expectancy that is up to 90% of a normal individual (Shavelle et al., 2015). As SCI requires long-term medical interventions, assessment and support for other factors is

important, e.g., personal and social interaction, and involvement of social workers, psychologists, physiotherapists, and occupational therapists.

Apart from the clinical assessment of TSCI, the International Classification of Diseases, 10th revision, Australian Modification (ICD-AM-10) coding system is used to provide further detail in the classification of SCI. International Classification of Disease is used globally to diagnose disease of body system. It uses an alphanumeric coding system, maintained by the World Health Organisation. The current system, implemented 1 July 2019, is the 10th version of Australian Modified (AM) coding system used throughout Australia (ICD, 2021).

A summary of how key muscle groups at each level are affected by lesions is described in Table 2.2, accompanied by their matching ICD-AM-10 codes.

Table 2-2 Expected functional outcomes of traumatic spinal cord injury (TSCI), with corresponding ICD-AM-10 codes

Level of TSCI – Key Muscle Groups	**ICD-10-AM**	**Expected Functional Outcomes of Complete Spinal Cord Injury**
C1-C3: Neck Muscles: Sternocleidomastoid, Paraspinal, Neck Accessory Muscles	S14.71 - S14.73	• Total paralysis in arms, torso, hands and legs • Loss of diaphragm function, ventilator dependent • Trouble controlling bladder and bowel function • Able to operate electric wheelchair with head/chin control
C3-C5: Neck/Shoulder Muscle: Upper Trapezius, Respiratory Muscle Diaphragm	S14.74	• Paralysis in the arms, hands, torso and legs • Trouble controlling bladder and bowel function • Able to breathe without ventilator • Able to operate electric wheelchair with head/chin control
C5: Shoulder Muscles: Deltoid, Rhomboids, Serratus Anterior (partial) Elbow Muscles: Biceps, Brachialis, Brachioradialis, Rhomboids, Serratus Anterior (partial)	S14.75	• May require assistance to clear secretions • Breathing will be weak • Can feed with help of devices (splints) • Able to assist with bed mobility and hoist transfers • Able to operate electric wheelchair with hand control for short distances
C6:	S14.76	• Absence of wrist flexion, elbow extension, hand movement; total paralysis of trunk and lower extremities • May require assistance to clear secretions

Shoulder Muscles: Pectoralis Major (partial), Latissimus Dorsi, Serratus Anterior Wrist Muscles: Radial Wrist Extensors		• Some physical independence and personal care with assistance (self-catheterisation for bladder management) • May be able to operate lightweight rigid or folding frame with modified rims
C7-C8: Elbow Muscles: Triceps Wrist/Hand Muscles: Wrist Flexors, Long Finger Extensors	S14.77-S14.78	• Paralysis of trunk and lower extremities, limited grasp/ release • May require assistance to clear secretions • Independent bed mobility • Independent personal care • Can use manual wheelchair • Able to drive with vehicle modifications
T1-T6 Trunk Muscles: Upper Intercostal, Thoracic Extensors	S24.71-S24.74	• Lower trunk paralysis and total paralysis of lower extremities • Compromised vital capacity and endurance • Independent daily living (ADL) • Able to live independently • Can use independent manual wheel chair • Able to drive with hand controls
T7-T12: Trunk Muscles: Abdominals, Lumbar Extensors, Lower Intercostal	S24.75-S24.76	• Paralysis of lower extremities • Intact respiratory function • Improving balance • Independent ADLs • Can self-manage manual wheel chair
L1-S5: Lower Limb Muscles: L1-L2 Hip Flexors, L3 Knee Extensors, L4 Ankle Dorsiflexors, L5 Long Toe Extensors, S2 Ankle Plantarflexors	S34.71-S34.75	• Paralysis of lower extremities, hips, knees, ankle, foot • Intact respiratory function • Able to self-manage personal care and ADLs • Can self-manage manual wheel chair • Able to drive and live independently
S1-S5	S34.7-S34.8	• S1 affects the hips and groin area • S2 affects the back of the thighs • S3 affects the medial buttock area • S4 and S5 affect the perineal area

As can be seen in Table 2.2, an accurate neurological assessment of the TSCI is imperative to support patients and their carers. Accurate assessment helps physiotherapists to plan and set target goals to help patients and provide correct support to them.

2.6.2 Cord Syndromes

Cord syndromes are part of the TSCI which affects certain blood vessels. They may also be non-traumatic if they result from stroke or compression from a tumor. Many TSCI patients can have multiple neurological functional injuries (S14.7x, S24.7x & and S34.7x) as well as cord syndromes (S14.1, S24.1x & S34.1x). Even though cord syndromes have very good prognosis in terms of recovery, they nonetheless present serious complications, depending on the types of injuries to the cord, and could cause significant morbidities and mortality after a TSCI. The aetiology and pathophysiology of five types of cord syndromes; central, anterior, posterior cord syndrome (CCC), Brown-Séquard Syndrome, together with matching ICD-10-AM codes, are explained below.

Spinal Cord Organisation

Depending on the region and level of injury to the spinal cord that is damaged there will be impairment of sensory, motor, and autonomic function. Types of lesions can be divided into two categories depending on the injury. If the lesion is located in the spinal cord itself, it is called an *upper motor neuron lesion*. Figure 2.3 is an illustration of the normal spinal cord tracts showing the major ascending (left half) and descending (right half) pathways. If the lesion involves the anterior horn cell or nerve roots, it is called a *lower motor neuron lesion* (Figure 2.4) A patient may have a combination of upper motor neuron and lower motor neuron injuries (Jacobson and Marcus, 2011).

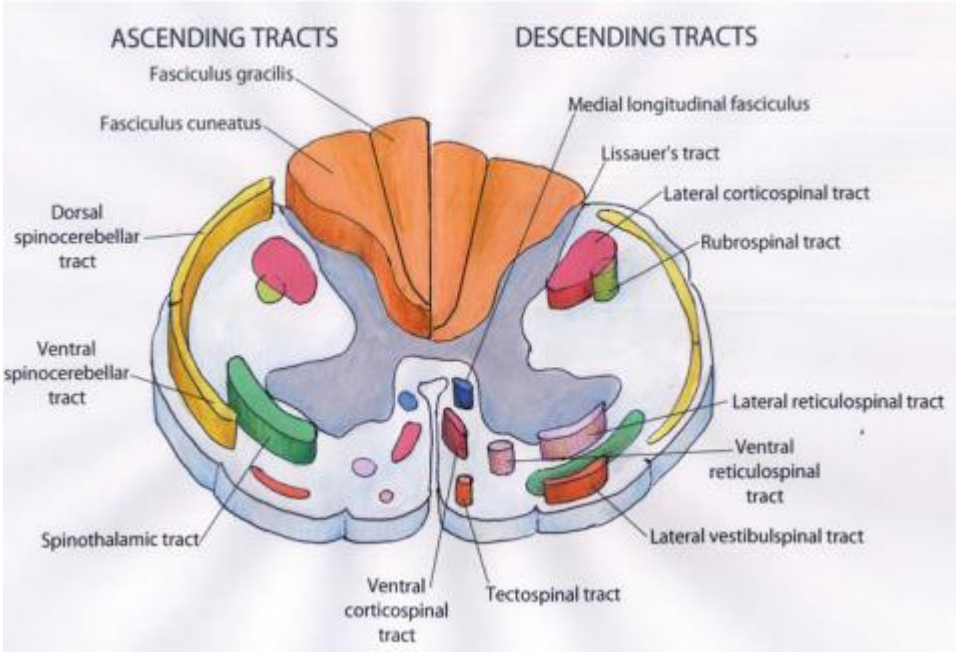


Figure 2-3 Normal spinal cord tracts: (Jacobson and Marcus, 2011)

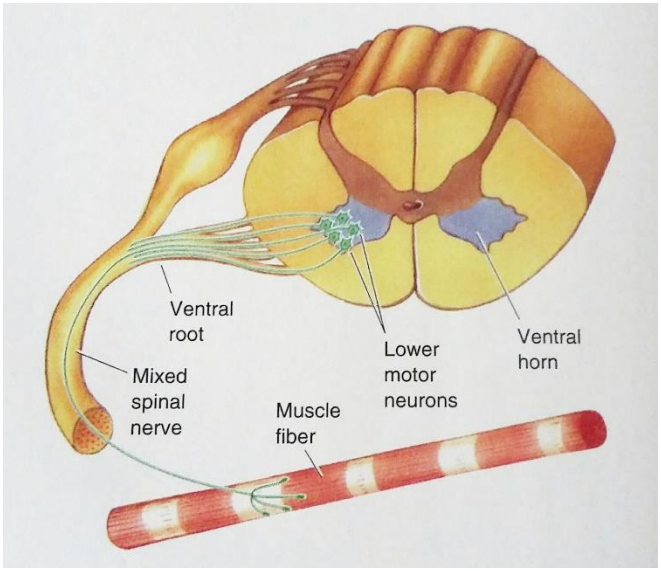


Figure 2-4 Lower motor neurons and nerve roots emerging from spinal cord (Bear et al., 1996)

Figures 2.5 - 2.9 illustrate each type of cord syndrome, which affects mobility and sensation differently.

Central cord syndrome (CCS) – S14.12

Central cord syndrome occurs in 15-25% of all TSCIs. The overall ICD-AM-10 code for all cord syndromes is S14.12. Central cord syndrome is the most common form of cervical spinal cord injury. The middle of the cord (central grey matter) is affected (brown circle). (Figure 2.5). This region of the spinal cord contains the nerve cells that are the target of descending pathways from the brain which are important for motor function (anterior horn cells), as well as those which receive sensory information from the limbs which is conveyed to the brain via the ascending pathways. This type of injury leads to a lower motor neuron injury because it affects the anterior horn cells and has a severe effect on hand and arm movements.

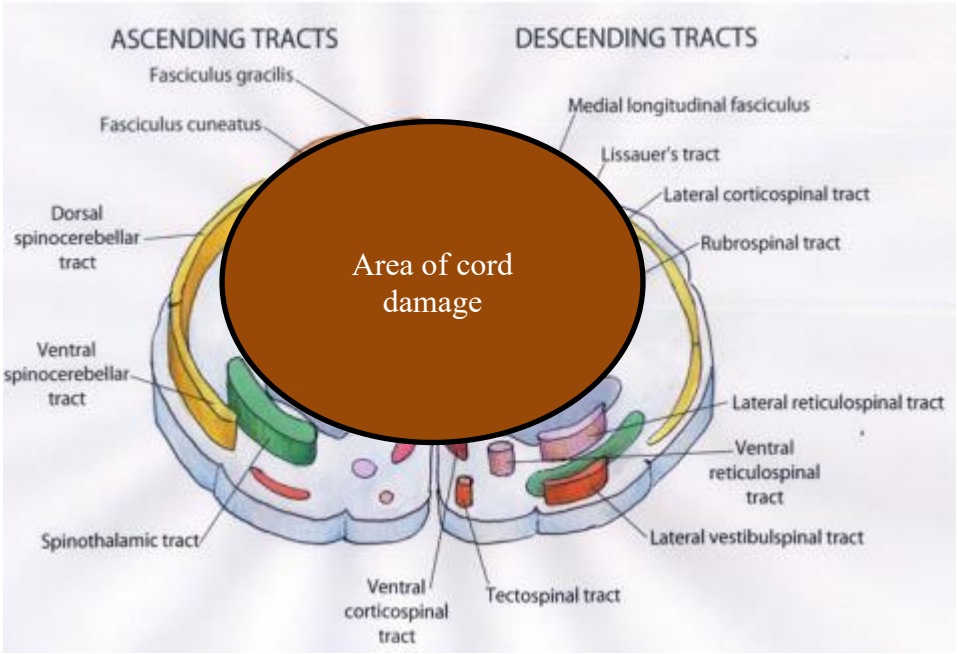


Figure 2-5 Central cord syndrome (injury shown in dark brown) (Jacobson & Marcus, 2011)

Elderly patients are more likely to experience a central cord syndrome as a result of a fall. The prognosis is dependent on age, and there is usually better recovery in younger patients (Schadler et al., 2016).

Brown-Séquard Syndrome (BSS) – G83.8

Brown-Séquard syndrome was described by Charles-Edouard Brown-Séquard in 1855. It is a hemi-cord injury where patients will have damage to the dorsal column, corticospinal tract and spinothalamic tract on one side as shown in Figure 2.6. The corresponding ICD-AM-10 code for BSS is G83.8.

Patients present with contralateral loss of pain and temperature, and ipsilateral loss of motor control and proprioception. There may also be loss of bladder and bowel control (Berman, 2018).

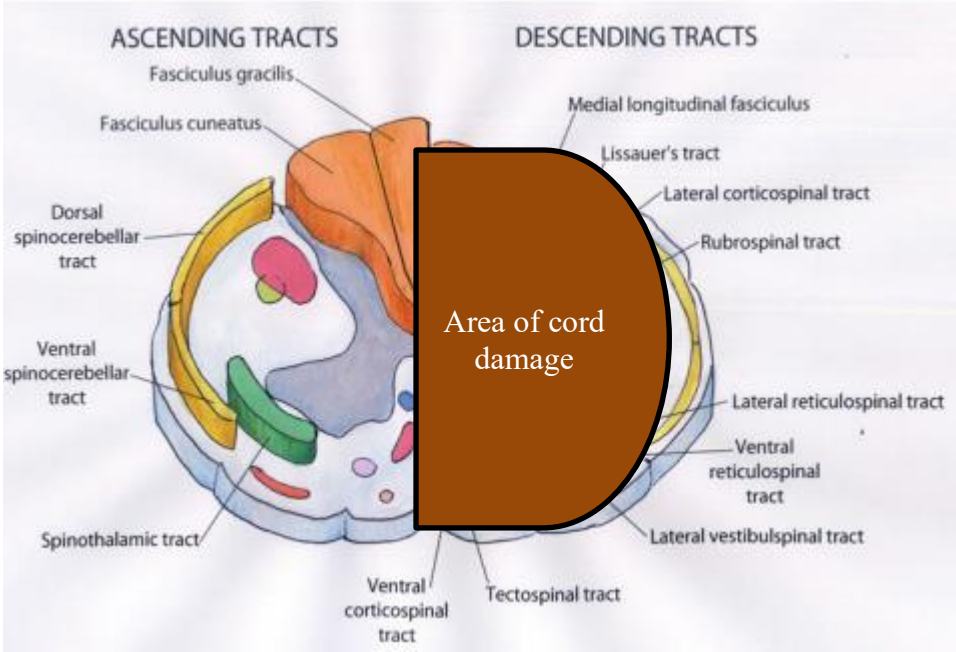


Figure 2-6 Brown-Séquard syndrome (injury shown in dark brown) (Jacobson & Marcus, 2011)

This syndrome may result from a knife or bullet injury. The overall prognosis for recovery is best compared to other SCI syndromes (Moskowitz, 2018).

Anterior Cord Syndrome (ACS) – G83.82

Anterior cord syndrome occurs as a result of flexion injury or injuries to the anterior spinal artery (Figure 2.7). The corresponding ICD-AM-10 code for ACS is G83.82.

The anterior spinal artery arises from the distal vertebral artery and is thought to be the major blood supply to the anterior two-thirds of the cervical cord. Anterior cord syndrome may happen as a result of atherosclerotic disease in the elderly or secondary to cross-clamping of the aorta during abdominal surgery. The posterior part of the spinal cord is not affected so the proprioception and vibration senses are intact.

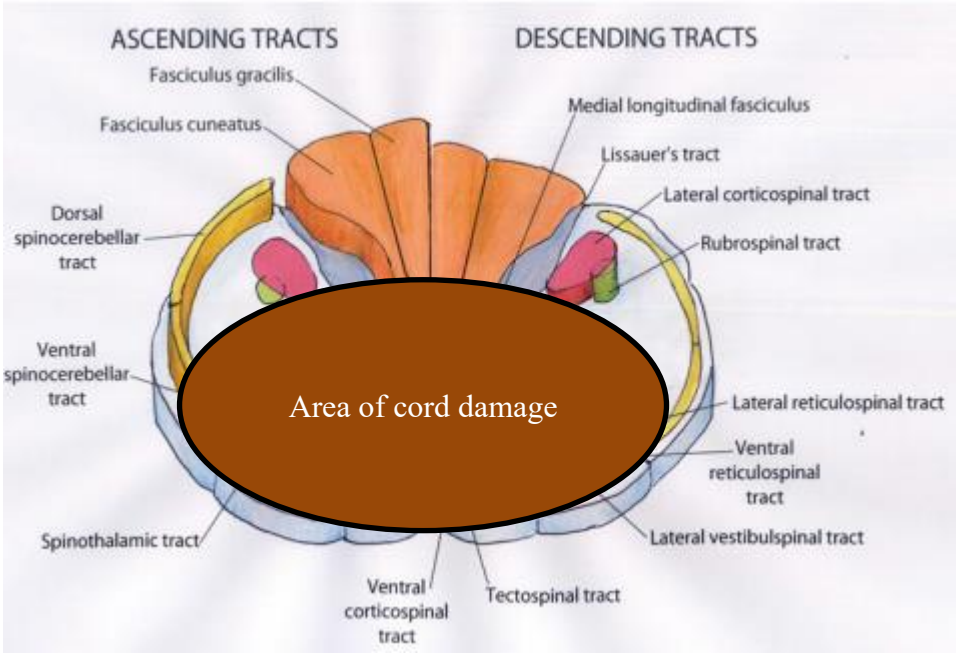


Figure 2.7 Anterior cord syndrome (injury shown in brown) (Jacobson & Marcus, 2011)

The clinical presentation may include:

- Variable loss of motor function
- Bilateral loss of pain and temperature
- Preservation of light touch sensation
- Urinary incontinence

The aetiology may be hyperflexion, disc protrusion or anterior spinal artery occlusion. The prevalence of ACS is 2.7-3% of all TSCIs. ACS has poor prognosis for recovery, with only 10-20% of patients having any motor recovery. Motor recovery is better in patients with preservation of touch and pain sensation (Tolia et al., 2020).

Posterior Cord Syndrome (PCS) – G83.83

The posterior cord syndrome is caused by a lesion in the posterior part of the spinal cord resulting from damage to the posterior spinal artery as shown in Figure 2.8. The corresponding ICD-AM-10 code for PCS is G83.83.

PCS can cause interruption of transmission of (a) sensory information to the brain and (b) motor commands from the brain to the periphery.

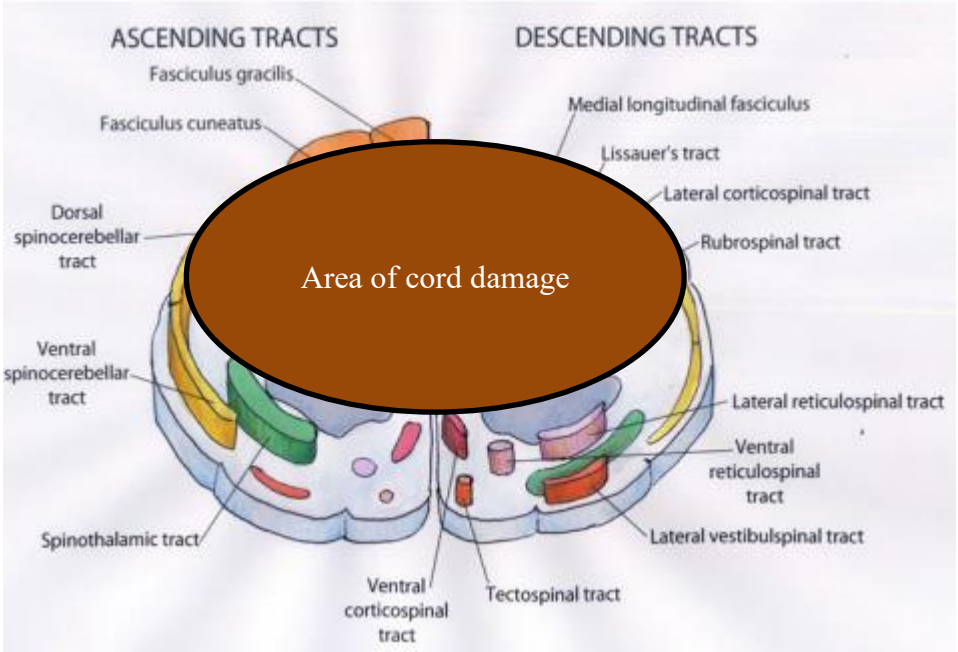


Figure 2-8 Posterior cord syndrome (injury shown in brown) (Jacobson & Marcus, 2011)

This is the least common of all cord syndromes, with an incidence of 2% (McKinley et al., 2021). The clinical presentation involves:

- Preservation of pain, temperature and movement. If the lesion involves the corticospinal tract there will be loss of movement
- Loss of light touch
- Loss of proprioception and vibration sense

The aetiology can include trauma to the neck and occlusion of spinal cord artery. The prognosis for ambulation is poor (McKinley et al., 2021).

Cauda Equina Syndrome (CES – S34.1) & Conus Medullaris (CM – 34.3)

Cauda equina syndrome (CES), ICD-AM-10 code S34.1 and conus medullaris (CM) ICD-AM-10 code S34.3 are conditions caused by injury of nerve bundles emerging from the distal portion of the spinal cord.

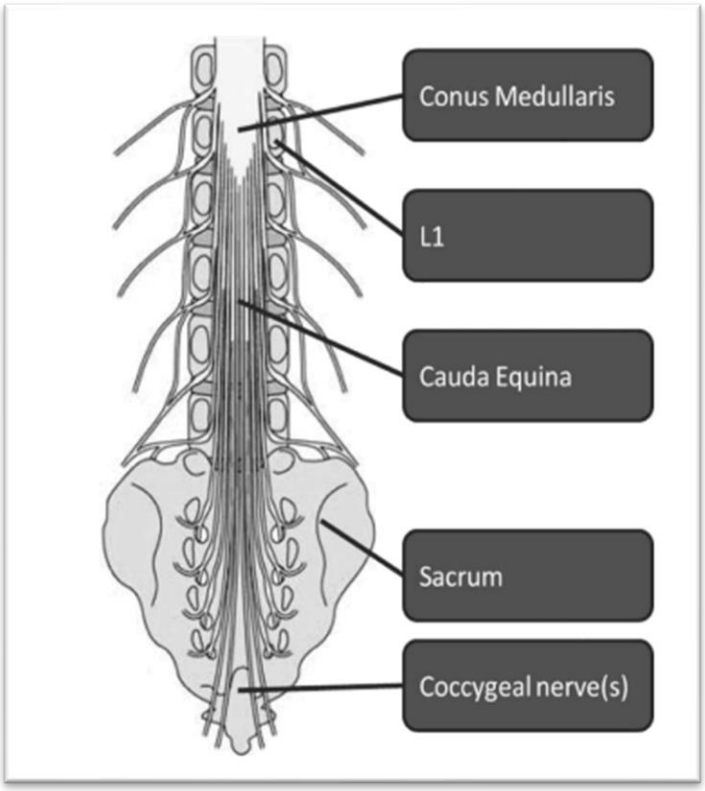


Figure2.9 Conus medullaris and cauda equina (Kirshblum et al., 2011)

The cauda equina, Latin for horse's tail, is the bundle of nerves that branches out from the lumbar and sacral spinal cord segments. It travels downwards to emerge through the lumbar and sacral vertebral foramina as in Figure 2.9.

CES is a lower motor neuron injury and results in true paralysis of lower limb muscles and loss of sensation, including saddle numbness: loss of sensation around the anus and/or genitals. The bladder, bowel and sexual dysfunction resulting from CES differs from that resulting from injury to the spinal cord itself.

Conus medullaris is part of the central nervous system, located at the L1-L2 vertebral level. Injury to this area impacts the sacral cord. Due to the close proximity between CES and CM, certain pathology may cause mixed symptoms. While CES affects the peripheral nervous system, CM

affects upper motor neurons, and leads to bowel, urinary bladder and sexual dysfunction (Kirshblum et al., 2011).

2.7 **Comorbidities**

People with SCI are known to have a higher prevalence of comorbidities than the general population. Their risk of developing other comorbidities such as cardiovascular disease, diabetes mellitus and various lipid abnormalities is also greater (Ayyub et al., 2015). Together with the normal aging process, these chronic diseases compromise general health status, impose further disabilities and pose a big burden on the national health budget. The Australian Institute of Health and Welfare (AIHW) reports that Australians diagnosed with one or more chronic conditions often have complex health needs, die prematurely and have poorer overall quality of life (AIHW, 2021). The AIHW reports five acute injuries (SCI, traumatic brain injury, severe burns, osteoporosis & self-harm and anxiety/depression), which can lead to chronic injury requiring long term medical intervention (Cripps & Harrison, 2008).

In the United States of America, a survey was performed to investigate the prevalence of comorbidities in members of the Paralyzed Veterans of America (PVA). The PVA was formed in 1946, for the soldiers who had returned from World War II with spinal cord injuries. The average age of the soldiers was 36 years and they had sustained injuries over 24 years previously. The study found that 25% of the respondents were obese. Common comorbidities amongst them were high blood pressure (49% vs 26%), high cholesterol (47% vs 30%) and diabetes (19% vs 7%) compared to control groups respectively (Hamid et al., 2018).

2.7.1 Cardiovascular complications

Individuals with SCI may experience problems with blood pressure and the ability to control temperature and sweating (Spinal Cord Injury Resource Center, 2011). Pneumonia, sepsis and renal failure used to be the most frequent causes of premature death in SCI patients, but with improved health management cardiovascular disease (CVD) is now the most frequent cause (Cragg et al., 2013).

People with SCI are more prone to having CVD compared with individuals without SCI. The prevalence of heart disease was 17.1% in SCI patients compared with 4.9% in able-bodied people.

Similarly, the incidence of stroke was 5.7% in SCI patients compared with 1.1% in non-SCI individuals in a study compiled from 60,000 individuals in a Canadian Community Health Survey (Cragg et al., 2013).

The risk factors for CVD identified in a previous study were dyslipidemias, diabetes mellitus and hypertension, as well as physical inactivity and smoking (Ayyub et al., 2015). Patients with SCI have three times more risk of CVD as a result of immobility and autonomic dysfunction causing blood pressure instability. Many patients with SCI suffer from orthostatic hypotension (reduction in diastolic blood pressure of 10 mmHg or more when the body changes position), as well as extreme hypertension during episodes of autonomic dysreflexia (systolic blood pressure >20 mmHg above baseline, as a result of spinal cord damage at T6 or above). Both of these conditions can cause damage to blood vessels thereby increasing the risk of CVD (Sezer et al., 2015).

2.7.2 Respiratory complications and sleep apnoea

Respiratory complications are common with both acute and chronic SCI, and are common causes of death in those with cervical injuries. Studies report up to 67% of people with acute SCI experience severe respiratory complications within the first days after the injury, which includes conditions such as pneumonia (31.4%) and respiratory failure (22.6%) (Hagen, 2015).
Dependence on a mechanical ventilator in the Intensive Care Unit (ICU) is common for acute phases. Up to 84% of patients with injuries to C4 or above and up to 60% of patients with more caudal injuries require mechanical ventilators in ICU. Moreover, those with injuries in the thoracic region experience severe respiratory complications (65%) (Hagen, 2015).

Neuromuscular respiratory weakness is quite common in SCI, causing weakness of inhalation and exhalation, which can affect respiratory function and can cause increased sleep-disordered breathing. This leads to decreased flow rates, resulting in failure of effective airflow during sleep. In general, 1 in 5 adults have mild obstructive sleep apnoea and 1 in 15 adults have moderate obstructive sleep apnoea. Prevalence of sleep disorders have been observed in up to 25% of middle-aged males and up to 13% in males under the age of 30 years (Berlowitz et al., 2005). In people with tetraplegia however, approximately 60% are affected by sleep-disordered breathing (Chiodo et al., 2016).

Risk factors for sleep apnoea include obesity and increased neck circumference, which could cause upper airway collapsibility (Chiodo et al., 2016).

2.7.3 Neurogenic bladder

Neurogenic bladder refers to a lack of bladder control due to damage of the spinal cord or nerves responsible for carrying messages between the bladder and the spinal cord. The nature of the dysfunction and subsequent management depends on whether the injury affects the spinal cord (upper motor neuron injury) or the peripheral nerves (lower motor neuron injury). Injury to the sacral cord or cauda equina results in sphincter weakness, which can affect co-ordination of storage and voiding phases (Hamid et al., 2018). Many patients require assistance with emptying their bladder and often rely on urinary catheters. The quality of life of patients with SCI who are on urinary catheters is worse than those who can void spontaneously (Welk et al., 2019).

Six percent of patients with SCI develop bladder cancer several years after their SCI (at mean age of 50 years and within 24 years from the first injury). It was thought that the main cause of bladder cancer was the use of an indwelling catheter for more than 10 years. However, a recent study has shown that more than 50% of patients who have developed bladder cancer did not use a catheter, suggesting that neurogenic bladder rather than an indwelling catheter might be the main cause of that cancer (Hamid et al., 2018). Urinary tract infection and urinary incontinence are very common causes of hospital readmission (Gabbe & Nunn, 2016).

2.7.4 Bowel dysfunction

Bowel dysfunction is very common amongst SCI patients and pattern of dysfunction varies according to neurological impairment (Silver, 2011; Thietje et al., 2011). Hughes, (2014) reported that most of the 12,000 cases of SCI per year; in the USA lacked normal bowel functions. The common symptoms were constipation, abdominal pain, hemorrhoids, incontinence and autonomic dysreflexia.

A survey of people with SCI was conducted one-year post-injury on their management of bowel function. The results showed that the most common intervention was digital evacuation (56%) and up to 58% spent up to 30 minutes for bowel care episodes. Other common problems reported were constipation (39%), haemorrhoids (36%) and abdominal distension (31%). The survey concluded that lack of normal bowl function is most bothersome for SCI patients and rated bowel dysfunction

as a moderate to severe life-limiting problem, often restricting social activities and quality of life (Coggrave et al., 2009).

Most patients use bowel management programs and treatment is multifaceted including use of suppositories, controlled diet, fluid intake, laxatives, electrical stimulation and surgical treatment including stimulation of sacral nerves (Hughes, 2014).

2.7.5 Pressure ulcer (PU)

A pressure ulcer (PU) is an area of localized damage to the skin resulting from prolonged pressure. PU can lead to a loss of blood supply, which can cause necrosis, infection and lead to death at the end stage (Martin et al., 2013). It is one of the most common secondary complications faced by patients with SCI due to loss of motor, sensory and autonomic control (Kruger et al., 2013). Kruger et al. (2013) reports alarming result of up to 95% of adult patients with SCI experiencing at least one PU in their lifetime. PU causes a tremendous setback in life; it is one of the major sources of recurrent rehospitalization and delays in rehabilitation, and some (7-8%) can lead to death (Martin et al., 2013). No single factor can explain the high prevalence of PU, as there are many factors involved. The three independent risk factors for PU are lack of mobility, perfusion (affected by diabetes) and skin problems. There have been many guidelines to prevent and manage PU, and while there has been a noticeable improvement, it is recognized that skin care management is suboptimal and better self-management design methods based on sound theory are required (Baron et al., 2018).

2.7.6 Diabetes mellitus

Glucose intolerance is more common in patients with SCI. These patients have a slower metabolic system, possibly due to greater body mass index and obesity, which can lead to a high tendency for premature diabetes mellitus (Montesinos-Magraner et al., 2018). A study showed active SCI patients had fewer comorbidities than inactive SCI patients, and that active SCI patients had fewer cardiovascular problems. The study was based on 60 minutes of physical activity per week in a small sample and did not differentiate age ranges - for example, that a younger group might have fewer comorbidities. Nonetheless, the study shows a direct relationship between physical activity and comorbidity: that is, that active SCI patients have fewer comorbidities than inactive SCI patients, demonstrating the benefits of regular exercise (Montesinos-Magraner et al., 2018).

2.7.7. Depression

Depression is very common amongst people with SCI. One in five patients suffers from depression, almost five times more than the general population (Hoffman et al., 2011). Similar findings were reported by William and Murray (2015), who investigated the prevalence of depression based on a meta-analysis of 19 studies and reported that average depression of those with SCI is higher than the general population, with a mean prevalence of approximately 22.2% (range18.7% to 26.3%).

Sauri et al. (2017) surveyed 831 participants with TSCI and NTSCI and found that 16.2% had depression. The rates of depression in NTSCI were double those of TSCI, at 12.4 % and 6.5% respectively. The study reported a high level of suicidal ideation, 19% of the total sample. Similar findings were reported among veterans with SCI in the USA; health administrative data showed that 28% (n=11,506 out of 41,213) were diagnosed with depression and 70% had another psychiatric illness. These veterans received more pharmaceutical prescriptions, and more healthcare visits than their counterparts (Ullrich et al., 2014).

Often depression is an underlying risk factor for suicidal ideation. Nam et al. (2013) studied suicidal ideation in 368 individuals with SCI and 1104 individuals without SCI (control group) in Korea. Suicidal ideation was 34.8% for SCI and 10.4% for the control group, and being female and having depression were the risk factors. There was no correlation between level or completeness of injury and suicidal ideation (Nam et al., 2013). However, suicide can be associated with culture. While an increase has been reported in Korea, there is a lack of data in non-western cultures to compare it with (Kim et al., 2013).

Risk factors associated with suicide were reviewed by Kenney and Garmon-Jones (2016) from published papers for the period of 1990-2016. A large proportion of the SCI studies report psychiatric disorders as a significant risk factor pre- and post-SCI. In a study of six individuals who committed suicide, five had developed moderate to severe depression as inpatients. These patients also had schizoid and narcissistic personality traits, as well as a history of alcohol/drug abuse (Kennedy & Garmon-Jones, 2017). Notably, many SCI patients suffer from anxiety more than the able-bodied population due to physical injuries, as well as ongoing secondary life-threatening consequences. More than 45% of the injured report excessive anxiety, fear and panic. Anxiety has a strong correlation with depression and suicidal ideation, highlighting the importance of routine psychological assessment during rehabilitation to ensure appropriate support is provided (Le and Dorstyn, 2016).

After discharge from the trauma centre, many patients go through lengthy rehabilitation. Many are seen by local GPs for various recurrent infections and then are referred back to local hospitals. Maintaining records of details of different medical conditions associated with a patient often poses challenges because of the constraints of data management systems. About 60% of people with SCI are wheelchair-dependent and there are social problems associated with this, including social obstacles (poor access to transportation, limited social opportunities) and psychosocial complications (life satisfaction is adversely affected).

A recent survey of SCI in Australia showed that life expectancy after SCI has risen from 34 years to 40 years and this is expected to grow. Together with other chronic disease, this will burden health expenditure heavily (AIHW, 2012).

Complications of SCI range from motor and sensory deficits to dysfunction of cardiovascular, pulmonary, urinary and gastrointestinal systems, as well as sexual control, depending on the level of injury. The long-term complications have a profound effect on psychological and socioeconomic wellbeing, increasing morbidity and decreasing quality of life. Long term support from family, friends and society is required.

2.8 **Health Costs of Spinal Cord Injury**

The average life span of a person with SCI is around 20-35 years and this is increasing with medical advances and a positive trend of survival beyond 12 months (AIHW, 2014-2015). The impact on both health expenditure and social burden is high, as there is high dependence on society for both social welfare support (ABS, 2011) and clinical support. The cost to society is profound. According to the latest report commissioned by SpinalCure Australia, there are total 20,800 Australians living with SCI and total cost in personal, and health as well as lost productivity amount to $74.5 billion, $3.7 billion per year (SpinalCure Australia, 2021). Most patients bear half of those costs ($31.4 billion) either by themselves or paid by family or friends. The government pays for half of the cost through services such as welfare programs, health care and income support. The Federal Government supports 48.7% of direct payment through Centrelink, Medicare, Commonwealth Home Support program and aged care. The State Government supports funds that are related to motor vehicle injuries or injuries sustained at work (SpinalCure Australia, 2021).

A study on the mortality and life expectancy of people in NSW who acquired a SCI showed a decline in mortality for people with tetraplegia from 9.1% (1975-1984) to 6.6% (1995-2006). A significant decline in mortality was noted for those with complete high-level injury (C1-C4) from 32.4% to 13.5% over a similar period (Middleton et al., 2012). Young age cohorts from 18-24 years account for 23% of total lifetime costs ($17.6 billion) as they have 51 years of life remaining (SpinalCure Australia, 2021). A severe level of tetraplegia has average lifetime cost of $8.5million per person. People with tetraplegia have an average lifetime cost of $8.5 million per person. Tetraplegia leads to loss of movement in the lower limbs, and little or no movement in the upper limbs. Hence, pressure ulcer is common due to lack of movement, and infection can lead to rehospitalization. Lack of mobility has a severe impact on independence and return to work (SpinalCure Australia, 2021).

Many patients with SCI develop secondary conditions that require frequent visits to hospitals. The most common causes of visits are urinary infections, pressure ulcers and fractures. The frequency of visits and costs were studied by Gabbe & Nunn (2016) from administrative health data on 356 patients in Victoria over the period 2008-2011. The study showed that almost 40% visited an Emergency Department twice and 27 % visited at least once during the two-year period post-SCI. The total costs of readmission were AUD$5,553,004 and AUD$87,790 respectively (Gabbe & Nunn, 2016).

The report on disability support services provided under the National Disability Agreement shows an increase in the use of services by 47% in the period from 2004-2005 to 2009-2010 (AIHW, 2013). Despite the significant disability resulting from SCI, only 0.7% of total research funding was put aside for research into SCI compared with 22.5% for cancer (Stepahead, 2021).

2.9 Gaps in Australian reports

Whilst Australia is one of the leading countries, along with the USA and Canada, as far as SCI registers are concerned, there are gaps in our system:

National registries: Even though Australia has a national registry the Australian Spinal Cord Injury Register (ASCIR), not all TSCI are captured in these data. There are in total seven participating Spinal Units in Australia which send information to the National Injury Surveillance Unit (NISU). In Victoria for instance, the Austin Hospital is the only hospital that reports to

ASCIR. The other major adult trauma centres, the Alfred Hospital (adult) and the Royal Melbourne Hospital, do not report to ASCIR. In addition, ASCIR does not include paediatric SCI. Thus, published data from ASCIR under-represent the extent of TSCI. The data from both the Alfred and the Royal Children's Hospitals are published under the Victorian State Trauma Registry (VSTR). Although Australia has one of the better registries compared to developing countries, results are incomplete. A coordinated national registry to capture all SCIs is needed.

SCI-Unspecific: For all published data from ASCIR, the results are based on discharge diagnosis. To a have full neurological examination patients need to be well enough to cooperate. Many patients are not completely well enough to receive an AIS classification.

Residency: Most published papers do not discuss the region where patients live, although the place of injury is discussed. The place of injury provides the information about the accident; for example, whether traffic-related, work-related or an occupational health and safety issue. Recording the place of residence is important in providing continuous support once patients are discharged, as continued support is required by all patients. Traffic accidents that are related to work are reported to the Transport Accident Commission (TAC) as traffic accidents. The TAC is another government body that is separate from the SCI registry.

Readmissions: There have not been any published reports on the patient journey over time. Most published papers provide information on readmissions within one year (Gabbe et al., 2016) and two years based on total count of comorbidities rather than following individual journeys.

Comorbidities: To my knowledge, there have not been any papers published on the relationship between TSCI and comorbidities.

Patient Journey: Published articles frequently do not report a patient's complete journey but only the first admission. To gain a full picture of the problems involved, the journey of patients requiring extensive follow-up is necessary.

2.10 Conclusions

This chapter has provided an overview of the epidemiology of SCI, both locally and internationally, highlighting disparities in reports from many countries, especially low-income countries where

there is a lack of national registries, hence caution is required for the accuracy of figures from these countries.

Pathophysiology of SCI, including the classification, has been described. The International Standards for the Neurological Classification of Spinal Cord Injury, which are used worldwide, provide consistent terminology and standardized assessment. The lifespan of patients with SCI is increasing along with the aging population. The complications of SCI and comorbidities for SCI post-injury have been outlined.

For patients with SCI, a good quality of life and full participation in society is possible provided proper medical and social supports are available. In higher income countries, these types of supports are available. Patients in low-income countries might not be able to survive and receive the treatment that is required to live a full length of life (Furlan et al., 2013; Singh et al., 2014).

Chapter 3

Clinical Data Linkage (CDL)

3 CLINICAL DATA LINKAGE (CDL)

3.1 Introduction

The concept of data linkage was first suggested by Dunn, chief of the United States National Bureau of Vital Statistics in 1946, where he suggested that each person creates a 'book of life', which has everything about the person from birth to death. Record linkage is a process of assembling the individual book into a volume (Dunn, 1946).

Traditionally, scientists have worked with a single defined dataset that is clean and specific for their research purposes. Today, however, research scientists are gaining a lot of value and knowledge from linked multiple datasets:

> *"Linkage holds significant promise in providing scope to extend performance measurement into areas where current data provide only a partial view."* (BHI, 2015, p.2)

The science of data linkage has grown exponentially post-World War II, with more data available electronically with the advancement of computational power. The initial data linkage was used for government, industry and academic areas, typically matching people, organizations and addresses across one or more lists; and this has been extended to multiple areas (Asher et al., 2020).

The explosion of data linkage has been possible with the advancement of computer technology, in both software and hardware capabilities. It is possible to store a large amount of data in a secure repository, handled by trained data custodians from the linkage units. Privacy, confidentiality and security of datasets are strictly guided by regulations in each country. Researchers have to meet ethics requirements before data are released.

The value of data linkage has become more noticeable during the last two decades and there has been a significant increase in the establishment of data linkages in many countries. The important milestones of data linkage are shown in Figure 3.1, in chronological order. The best practices and gold standards of data linkage or record linkage will be explained following paragraphs with examples.

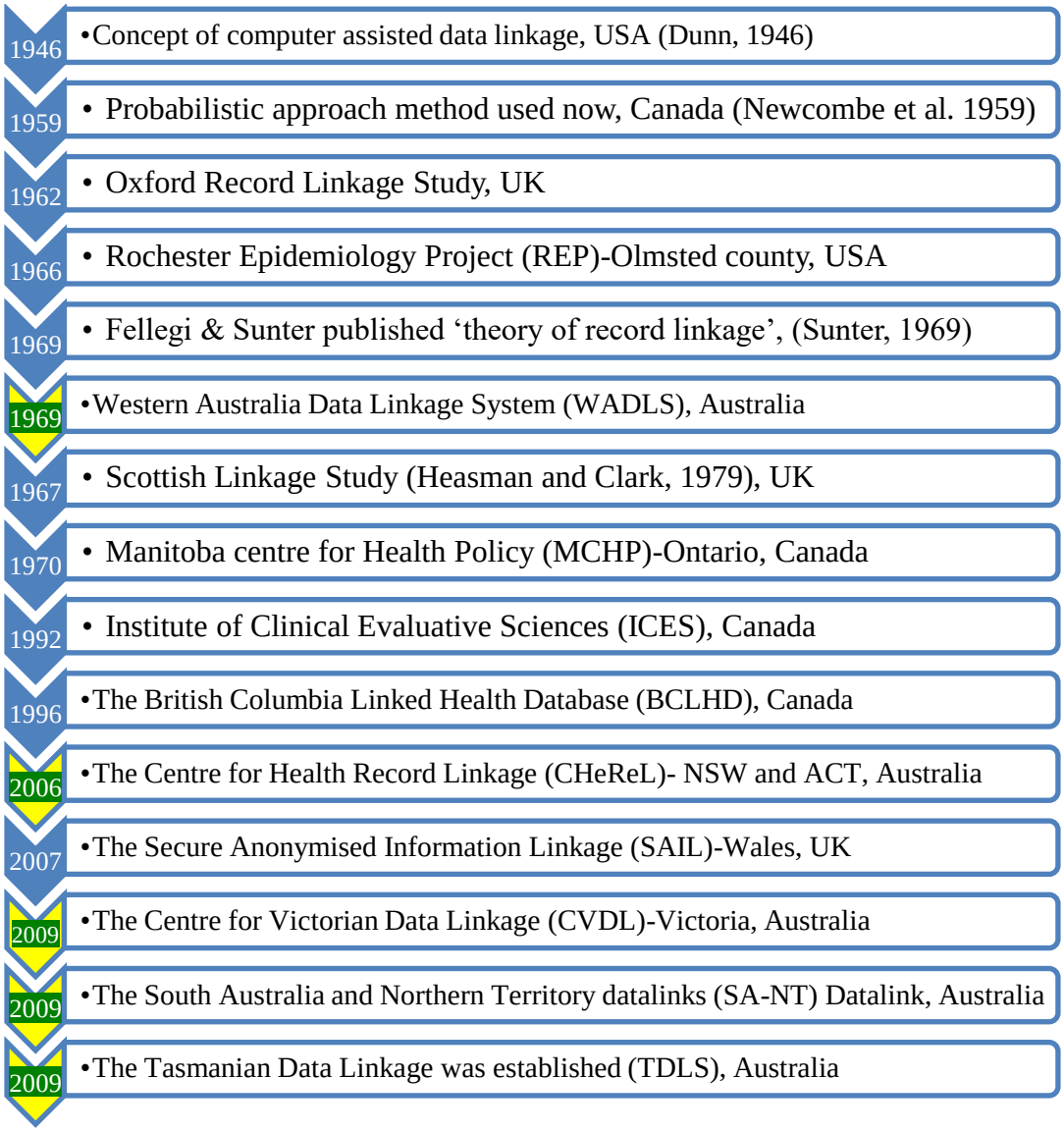


Figure 3-1 Important milestones in history of data linkage

This chapter discusses the current state of CDL in Australia and internationally. There are challenges involved with CDL with respect to privacy, and ethical and social issues, anonymization, information sharing and central information repositories. Associated gaps in knowledge and future directions are also outlined.

3.2 **Data Linkage Methods**

> *The application of medical records to serve only their own section of the Health Service is outdated - the individual is the unit and not the section of the Health Service. P. Bothwell (1961) in* Acheson & Evans, 1964, p.8)

Clinical Data Linkage (CDL) is a technique for creating links between pieces of information that are thought to belong to the same person. It uses a statistical tool which allows linking of datasets kept in different locations that relate to the same individual, such as driver's license number, Medicare number and hospital unit record number (Christen, 2012). CDL is a very efficient method of providing valuable information about causes of disease, early intervention and treatments, and effective management of diseases, and can be used to educate clinicians and the wider community. This method has been powerful in population health in identifying risk factors and evaluating preventative measures and treatments for various diseases (Emery & Boyle, 2017). A good example occurs in the health field where cross-referencing of different health information sources is needed, but the art of record linkage can be quite challenging if there are multiple data custodians involved and if the infrastructure of the health system is heterogeneous.

A theory of record linkage goes back to 1969, when Fellegi and Sunter introduced mathematical algorithms, based on decision rules, to link two or more sets of data that belonged to the same entities (Fellegi & Sunter, 1969). The Fellegi and Sunter model compared the relative frequency of strings: for example a surname that is relatively rare in pairs of records taken from two files has more distinguishing power than a common one (Winkler, 1989). More complex methods of CDL are often needed because individual identifiers (e.g. an individual's driver's license number, health identifier number, hospital unit record number) are unique in different settings and may not be able to connect different services (Christen, 2012; Christen & Churches, 2006).

An important aspect of CDL is that the method selected for data linkage depends on the types of datasets involved. There are two main techniques used in clinical data linkage: deterministic and probabilistic linkage. A combination of both techniques has been used in various projects, and the linkage variables will depend on the datasets being used.

3.2.1 Deterministic data linkage

Deterministic data linkage is the oldest method, a rule-based approach where a unique identifier or group of identifiers across the database is available. In this method, a high degree of certainty

involving unique identifiers such as driver's license, Medicare number or unique hospital ID is required. This method is robust if there is a unique national identifier that is well coded (Christen, 2012; Karmel et al., 2010). However, when a unique identifier is unavailable, it is possible to incorporate similarity measures, such as strings - for example, comparing date of birth and matching this with first and last names from two different databases in an effort to increase validity.

The deterministic method is often used when the data are noisy and a high threshold of accuracy required, as it does not tolerate error and may miss many true linkages. When the threshold is set too low, it is overly sensitive, generating falsely matched records. It is possible to adjust the threshold such as taking the first three digits of a zip code instead of an exact match on zip codes; however, this can lead to false positives (Li & Shen, 2013).

3.2.2 Probabilistic data linkage

Probabilistic record linkage has been developed over the last 70 years; it involves linking two (or more) records based on the probabilities of agreement and disagreement between ranges of matched variables such as last and first name, birth date, gender, race, ethnicity and place of residence (Asher et al., 2020).

In 1969, when comparing two sets of data, Fellegri and Sunter (1969) used concepts in which the probabilities of having true matches (M set) and the probabilities of having non-matches (U Set) are *m* and *u* probabilities. For example, if the population has the same number of males and females, then the probability *u* would be 0.5, *u* probability being unmatched. Likewise, a variable such as Medicare number will have a very low *u* probability because it is unlikely that different individuals have the same Medicare number. Fellegi and Sunter defined weights based on the measurement of the contribution of each field to the probability of making an accurate classification into M and U sets. When there is agreement between the two records, the weight is calculated as *log2(m/u),* whereas when there is disagreement, the weight is calculated as *log2((1-m)/(1-u))*. For instance, a match between a common last name will provide a lower agreement weight than a match between an uncommon last name (DuVall, Kerber & Thomas, 2010).

The probability matching techniques underpinning record linkage bring together records on an individual patient using key identifying information on each record. The accuracy of probabilistic record linkage is variable. Many researchers report varying degrees of success in using the probabilistic approach. A systematic review of probability-based data linkage reported that

accuracy ranged from 74% to 98% (Silveira & Artmann, 2009). Jebamani et al. from Manitoba in Canada reported a 99% match on gender, a 70% match on surname, a 94% match on given name, and a 96% match on birth year (Jebamani, Burchill, & Martens, 2005). Bohensky et al. reported stated that the impact of false negative and false positive linkages must be considered when interpreting results (Bohensky et al., 2010).

3.3 Clinical Data Linkage – International

Many countries have developed infrastructure to link data to create extensive databases, but only a handful of countries have the infrastructure to sustain and support such activity (St. Sauver, 2011). Among English-speaking countries, data linkage system facilities exist in UK, Canada and Australia. However, limited linked databases exist in the USA, because it has no national health system (St. Sauver, 2011).

3.3.1 United Kingdom (UK)

The UK has been leading data linkage for decades. Well-known linkage systems are the Oxford Record Linkage Study (ORLS), the Scottish Linkage Study and the SAIL system.

Oxford Record Linkage Study (ORLS)

In 1962, a medical record linkage system was first established in England by Sir Donald Acheson. Linkage started in 1963 with a project called the Oxford Record Linkage Study (ORLS), which connects birth, mortality and morbidity of the Oxford Region of 2.5 million. From 1963 to 1979, ORLS became the basis of the National Health Service statistics. In 1979, Michael Goldacre became head of the unit and initiated a series of reports for every hospital and every health authority. Ad hoc service of up to 1000 requests a year was provided (Goldacre, 2000).

Since 1998, all deaths and hospitalization data across the whole of England have been linked (Goldacre, 2000). In 1999, a legal framework to protect privacy was brought in, where the researchers were asked to obtain consent from individual patients. Identifiers in ORLS were stripped off and the NHS identifier was used as unique identifier. In 2003, the Health and Social Care Act was brought in, to ensure that research could continue without written consent from the individuals.

With funding from the National Institute for Health Research the Oxford Group continues to undertake English national linkage on a variety of national programs such as linking hospital and mortality data (NHIS, 2014). The linkage uses a NHS identifier, patient details such as date of birth (DOB), sex, postcodes and local patient identifier but does not include patient name, full street address, marital and social status, occupation or pharmacological treatment. This database has provided information about health care utilisation and epidemiology of disease (Acheson & Evans, 1964). Record linkage of patient data has now expanded worldwide. It has been successfully used to identify health indicators in population studies and epidemiological studies in medicine for the prediction of diseases and associated trends for treatments.

Current projects include investigation of long-term trends, perinatal studies, heart attack and multiple sclerosis related diseases, to name just a few.

Scottish Data Linkage Study (SDLS)

Scotland has a strong track record for performing linkage for research purposes, owing to routinely collected and well-maintained national administrative health data sets. The Scottish record linkage system and organizations like the Information Services Division of NHS National Services Scotland centrally holds permanently linked patient-based databases (SDLS, 2021). A decision was made in 1968 to keep all patient details from hospital discharge records, death records and cancer registrations to keep in a machine-readable form. This would include patient identification information such as names, dates of births and places of residence (Heasman & Clark, 1978).

In the 1980s, with increasing computer power, it was possible to envisage a system that could link massive data into one place. Development of the current system began in 1989 with new techniques and computer power. Use of new technology such as probabilistic method together with blocking technology minimised data matching errors but enhance the data quality (Walsh et al., 2001). A set of guidelines was established to protect data through the Data Sharing Code Practice and Identify Management and Privacy Principles (SDLS, 2021).

An example of a coordinated and well-integrated service in Scotland is where the National Health Service permits a child protection officer to share files with school or police so that the three services can be integrated to protect the child. Another case is where a local GP shares a patient's symptoms and diagnoses with a hospital so that the patient receives coordinated services throughout the National Health Service (SDLS, 2021).

The Secure Anonymised Information Linkage (SAIL)

The Health Information Research Unit at Swansea University in Wales recognised the enormous benefit of linking individual data for public health and health service delivery. As a result, the Secure Anonymised Information Linkage (SAIL) Databank was established in 2007 with funding from the Welsh government. The databank contains routinely collected anonymised data from individuals, with a vast array of health, education, housing and social information.

The datasets are remotely available, and security is protected and released to researchers with stringent guidelines. SAIL operates under strict guidelines of the UK Secure Research Platform (SeRP). Datasets are accessed under a secure research protocol. SAIL data are used for multiple purposes including evaluation of health policy and the provision of health services (Jones et al., 2019).

SAIL which has been used in over 300 projects to date, with about 30 new projects each year, has 1,200 registered users. A summary of the SAIL dataset is shown below in Table 3.1 (Jones et al., 2019).

Table 3-1 SAIL core datasets

SAIL core datasets		
Core Datasets	**Coverage**	**Characteristics**
Annual District Birth Extract	Since 2003	All births registered in Wales; 35,000 births per year
Annual District Death Extract	Since 2003	All deaths registered in Wales; 32,000 deaths per year
Critical Care Set	April 2006-May 2016.	Nation-wide critical care database, collected and coded at each hospital. 9,000 admissions per year
Diagnostic and Therapy Services Waiting Times	October 2005 - May 2016.	Waiting times for specified diagnostic and therapy services for the NHS in Wales, 120,000 records per year
Emergency Department	Since 2009	Health administrative data for all NHS Wales. 750,000 attendances per year
Child Health Database	Since 1987	Birth registration and monitoring of child health system.
Outpatient Dataset	Since 2004	Attendance information for all NHS Wales hospital outpatient.
Outpatient Referral	2009 – June 2016	Referral pathways to secondary care
Patient Episode Database for Wales	Since 1997	NHS Wales hospital admissions
Primary Care GP dataset	2000 – 2014	General Practices. Averaging around 5000 patients per practice,
Welsh Demographic Service Dataset	Since 1990	Administrative information about individuals in Wales that use NHS services, drawn from GP practices. approximately 5 million people
Active Adult Survey	2012 - 2013	Survey of the adult population in Wales on sports activities. Data on 13,000 individuals
Bowel Screening Wales	Since 2008	Administrative and clinical information for bowel screening,140,000 screening test records per year
Breast Test Wales	Since 1989	Administrative and clinical information for breast screening, 110,000 screening test records per year
Cervical Screening Wales	Since 1990	Administrative and clinical information for cervical screening, 225,000 screening test records per year
Congenital Anomaly Register and Information Service (CARIS)	1998 - 2011	Information about foetuses or babies who has or is suspected of having a congenital anomaly, collected by CARIS. 1,500 babies per year

SAIL core datasets		
Core Datasets	**Coverage**	**Characteristics**
Educational Attainment	2003 - 2015	Annual return submitted by all sectors including nursery, primary, middle, secondary and special schools, provided by Welsh Government. 470,000 records per year
National Survey for Wales	2012 - 2015	The Welsh Government's major survey of the general population in Wales covering a wide range of topics affecting people and their local area. 12,000 people per year
Welsh Cancer Intelligence and Surveillance Unit (WCISU)	Since 1972	National Cancer Registry for Wales to record, store and report on all incidences of cancer, collected by WCISU. 686,000 records
Welsh Health Survey	2013 - 2014	Information on the health and health-related lifestyles of people living in Wales, collected by the National Centre for Social Research. 4,400 records

SAIL has been used to provide insight into chronic diseases such as ankylosing spondylitis (AS). Ankylosing spondylitis is a chronic inflammatory arthritis which begins in young adulthood and has an impact on health utilisation mostly from early retirement as a result of pain associated with the condition (Cooksey et al., 2015). The study included General Practitioners' (GP) records, both inpatient and outpatient emergency visits including medical and surgical procedures. The results showed that the costs relating to early retirement and work absenteeism were the main contributing factors to the overall cost of AS, around £19,016 per person per year. This study was made possible by allowing two important sets of information to be linked. These sets were: (a) GP administration costs that are not available anywhere else to capture hidden costs, (b) access to information about expensive medication from medical records (e.g., TNF-inhibitors), which are prescribed and distributed by specialists in hospital-based rheumatology, not by GPs) (Cooksey et al., 2015). This study allowed better understanding of the hidden costs involved in chronic diseases such as AS. In addition to the linked administrative data his participants completed questionnaires about work and activity limitations and healthcare resource use. There were some discrepancies between self-reported visits to GPs (1.73 times) verses GP reporting (1.35), indicating that participants over-reported their healthcare visits. Methods to ensure more accurate recording of visits to GPs would be helpful for future studies.

As with every aging population, management of chronic disease is going to be a problem and very costly to the health budget. Hence capturing GP visits for individuals would add enormous benefits to understanding of health of the population. Currently SAIL has 195 GP practices out of 499

contributing to the SAIL databank. More contribution from GPs is expected in the years to come as the benefits to population health become more evident and the mitigation of risks of data security and confidentiality gain more acceptance.

SAIL has been designed with researchers in mind in terms of obtaining ethics approvals, funding and time to release the datasets without compromising security and confidentiality. The maximum time it takes to approve the datasets is 12 weeks (Mourby et al., 2019).

3.3.2 Canada

Canada has been at the forefront in record linkage from the early years. This has been possible because ten provincial and two territorial health insurance schemes are publicly funded and have adhered to national standards set at the federal level (Fair, 2004). In 1959, Canadian geneticist Howard Newcome and his associates recognized the full potential of computerized record linkage, which has the advantage of speed, consistency, reproducibility, and ability to handle large volumes of data (Newcome et al., 1959). Following on from Dunn's suggestion of the 'book of life', the National Index was formed, which had an extended arrangement of personal files into family histories and had listings of all major events linked from birth, through marriage to death (Acheson & Evans, 1964).

Manitoba Centre for Health Policy (MCHP)

In 1970, the Manitoba Centre for Health Policy (MCHP) initiated the Population Health Research Data Repository of the residents in that province; these are then linked with a scrambled identifier, which is unique to a family (not the individual) (PHRDR, 2021). These de-identified data are available to academics, researchers, clinicians, students and government staff. In the early days, the MCHP received funding from external agencies based on the topic of interest to the Department of Health and clinical experts. As with success of publications and recognition of the project, the funding has improved. Since 1991, funding from the provincial government has enabled further research by MCHP with many researchers affiliated with the University of Manitoba (Katz et al., 2019).

Researchers in Ontario and Manitoba now have excellent access to population data, which includes primary care, laboratory results, billing data, prescriptions, social service usage, census results and immigrant status. All data are linkable at an individual level. These linked health data

are routinely used by researchers, clinicians and students to predict health outcomes and by government officials for policy making. One powerful use of such linked data was the investigation of the association between neighbourhood walkability and the prevalence of obesity and diabetes (Henry et al., 2018). The study linked all the doctors' billing claims, hospital discharge data and postcodes of residents in Toronto and then applied an algorithm to the physician claims and hospital data to identify people with diabetes, and assigned a walkability index to each postcode. The results showed a correlation between diabetes and walkable distance rates, in that relatively low rates of diabetes were noted in the highly walkable central zones, and higher rates of diabetes in the lower walkability suburbs. Since this did not explain causality between a low walkable neighborhood and diabetes, a randomized trial was performed on more than 200,000 newly arrived migrants without diabetes who had moved to different areas of Toronto. The study showed that the incidence of diabetes was 58% higher among immigrants who had moved into the least walkable neighbourhoods. These findings have influenced the design of new housing developments in Ontario (Henry et al., 2018). There have been numerous publications from these linked datasets which can inform public policy and improve the health and wellbeing of communities.

Institute of Clinical Evaluative Sciences (ICES) - Canada

ICES was established in 1992 to study the health care system and delivery of better health to the 13.4 million residents of Ontario, Canada. All residents living in Ontario are issued with an Ontario Health Insurance Plan (OHIP) card, with which they can obtain free health services. This ten-digit card is linked both determinantly and probabilistically to the Registered Persons Database (RPD) in a secure network to capture all residents in Ontario (Schull et al., 2019). Since its inception 27 years ago, the repository holds 20 billion records. The major categories of datasets are shown in Table 3.2 below:

Table 3-2 Major categories of datasets held at ICES

Dataset Category	Key Examples
Health Services	In-patient hospital records (from 1988) Emergency department and ambulatory care (from 2000) Physician billings (from 1991) Electronic medical records† (from 2010) Homecare (from 1994) Laboratory test results (from 2007) Mental health and addiction services (from 2005) Same day surgery (from 1991) Long-term care, complex care and rehabilitation services (from 1996) Publicly funded prescriptions and all narcotics/controlled substances (from 1990)
Acquired Cohorts and Registries	Cancer (from 1990) Bariatric surgery (from 2010) HIV (from 1995) Perinatal (from 2006) Organ donation (from 1995)
Care Providers	Physician demographics, specialty and other training information (from 1992) Physician practice payment model (from 2005)
Coding and Geography	Drug, diagnosis and geography conversion and reference tables
Facilities	Information on health service institutions (from 1988)
Financial	Cost of health care services (from 1992)
Population and Demography	Vital statistics (deaths only) (from 1990) Refugee and immigration status (from 1985) Derived ethnicity data (algorithm-based) (from 1990) Census profiles (from 1991) Population estimates and projections (from 1981)
Surveys	Canadian Community Health Survey (from 2001) Ontario Health Study (from 2009) Health Care Experience Survey (from 2006)
ICES-Derived Cohorts	Asthma (from 1993) Cardiac (from 1991) Congestive heart failure (from 1991) Dementia (from 1996) Diabetes (from 1991) Inflammatory bowel disease (from 1991) Mother-baby pairs (from 1988) Patient-physician-hospital referral networks (from 2005) Rheumatoid arthritis (from 1993)
Non-Health Sector Data	Environmental, Transportation, Education, Government disability support

ICES is a registered charity, not-for-profit corporation under the Corporation Act. Under Ontario's Personal Health Information Protection Act, 2014, hospitals and physicians are able to provide patient details to ICES for the purpose of health research.

Canada is one of the few countries in the world that has a cancer reporting system for the entire population. This has been possible through cooperation between provincial and territorial registries, which have been providing data to Statistics Canada since 1969. This is the basis for the Canadian Cancer Registry, which records cancer incidence and survival data for each newly diagnosed primary cancer, including childhood cancers (Fair, 2004). In 2008, three cancer registries, the Ontario Institute for Cancer Research, Cancer Care Ontario, and Institute for Clinical Evaluative Sciences (ICES), were joined to form a new cancer data initiative, Ontario Cancer Data Linkage Project: "cd-link". This program linked de-identified datasets with comprehensive data use agreement and protection (Earle, 2014).

The British Columbia Linked Health Database (BCLHD)

The British Columbia Linked Health Database (BCLHD) was established in 1996 and provides researchers with de-identified and longitudinal data of 4.7 million residents in 2018. The funding for BCLHD comes from the Ministry of Health. The BCLHD has to comply with legislative acts governing protection and use of sensitive information. The Freedom of Information and Protection of Privacy Act (FIPPA) allows researchers to use personal information for research (Katz et al., 2019). The average time taken to receive linked data is four to six months depending on the size and variables (Ark et al., 2019). The datasets include medical services plans, PharmaCare, hospital separations, continuing care, birth registrations, death registrations, mental health episode records, workers' compensation, and the British Columbia Cancer Agency cancer incidence file (BCLHD, 2021).

The value of collaborative studies involving linkage of five database sets, Medical Service Plan (MSP), hospital separations, and perinatal statistics on deaths and births, has been shown in a number of publications. The first showed that place of residence had a direct link to birth weight. Living within 50 meters of a highway was associated with a 26% increase in small gestational birth weight, 11% increase in low birth weight, and 21% of babies were more likely to be pre-term (Brauer et al., 2008). Other studies showed that children brought up in areas close to high traffic were more likely to develop asthma (Clark et al., 2010), and bronchiolitis (Karr et al., 2009) and

cardiovascular diseases (Gan et al., 2010), which shows that this could partially be due to pollution from the traffic. This kind of study can be used as tools for designing residential planning and health promotion (Ark et al., 2019).

3.3.3. United States of America (USA)

The Rochester Epidemiology project started in 1966 and links all medical records of residents living in Olmsted County, Minnesota and Wisconsin in a single research database,

> "The REP allows the study of health and disease across the entire community, from birth to death, and from primary to specialty care."
> – Barbara Yawn, MD, REP Co-Principal Investigator 2006-2015 (REP, 2021).

The National Institutes of Health (NIH) provides funding to link data from more than fifty providers, including dental clinics. The data are available electronically and include demographic characteristics, medical diagnostic codes, surgical procedure codes and death information (St. Sauver et al., 2012).

In 1996, the state of Minnesota introduced a law to protect privacy and confidentiality (Minnesota state privacy law—Statute 144.335, amended in 1997). Under this law, Minnesota health care providers can have up to two attempts (60 days apart) to obtain consent from patients before medical records can be used for the research. If a patient does not respond to the request, authorization is implied and the record can be used. The authorization does not expire but a patient can cancel at any time. For patients who are under the age of 18, parents or guardians are asked to authorize the use of medical records.

The strength of REP is that it captures the entire population of Minnesota. The dataset includes sex, ethnicity, age, insurance and socio-ecnonomic status and allows for the study of the disease status of a wide range of conditions. The population is stable and research can follow patients for longitudinal studies. It is possible to to study patients from the initial diagnosis to final diagnosis without going through administrative data. However, due to the size of the population, study into rare conditions such as ovarian or cervical cancer are limited (Sauver et al., 2012). In addition, the REP is based on recording of serious medical conditions that have been brought to medical attention only, but does not include unrecorded conditions such as mild cognitive impairment or gastroreflux which could have an impact on the recovery of primary conditions later on. Thirdly,

the demographics of Olmsted County are not the same as those across the USA; hence, the study results are not necessarily generalizable to the rest of the country, and have to be considered case by case (Sauver et al., 2012).

Another big strength of REP is the total trust and satisfaction of the people of Olmsted county. A survey done in 2000 and repeated in 2010 shows that 85% of residents agreed to participate in providing their data to specific health providers. A further 13% agreed to participate with at least one provider, which brings total participation to 98%. Only 2% refused to participate with any providers, which means that this database really captures almost the entire health care information on Olmsted County population (St. Sauver et al., 2012).

The latest innovation of REP is using the web to obtain rapid data. The new REP Data Explosion Portal (REP DEP) has a summary of people living in 27 county regions of South Minnesota and western Wisconsin, covering a population of 694, 506, 61% of the total population. The portal contains 717 disease categories from 2009-2013, coded by diagnostic codes of the ICD-9[h]. The user can enter two categories of interest and is able to obtain sex, age and county specific prevalences of disease conditions (St. Sauver et al., 2018). It is quick and free however, the downside is that researchers should be familiar with ICD-9 codes, which are often quite complicated and normally only known to specially trained researchers (St. Sauver et al., 2012).

Most of the examples identified above are based on population studies linking one or two administrative datasets to look for trends in a specific disease based on interests of researchers rather than the full medical experience of people with specific diseases. The following section describes clinical data linkage in Australia and how linked data are used.

3.4 **Clinical Data Linkage – Australia**

Linking administrative health data in Australia has been recognized as an important resource for health services research and informing health policies. The Population Health Research Network (PHRN) is an Australian Government initiative to build infrastructure to enable key stakeholders to link de-identified datasets from a wide range of sources (PHRN, 2021). It is funded through the National Collaborative Research Infrastructure Strategy and its objective is to build a national infrastructure that supports linkage of population datasets for health and disease surveillance, so that policy makers and providers can respond effectively to the changing needs of the population (NCRIS, 2021). Researchers have to contact the PHRN Program Office for cross-jurisdictional

data linkage to obtain approval, information on the location of the datasets cost involved, acquisition and delivery timeframe, and referral to the data linkage units.

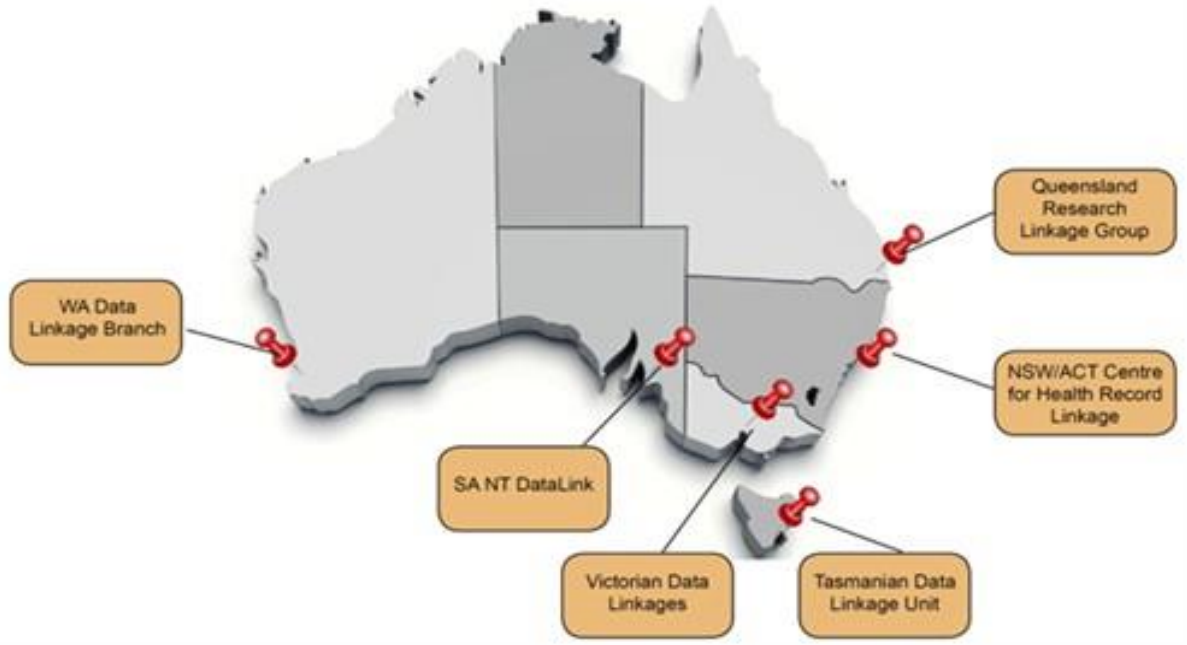


Figure 3-2 Map of Australian Data Linkage Centres (PHRN, 2021)

Under PHRN, there are six linkage centres in Australia, as can be seen in Figure 3.1. The Western Australia Data Linkage Systems (WADLS) leads data linkage in Australia and has a large de-identified prospective longitudinal population-based database involving probabilistic systematic record linkage of administrative health datasets for the total population of Western Australia (Holman et al., 2008; WADLS, 2021). Since the PHRN was formed in 2009, four new regional data linkage centres have been established: The South Australia (SA)/ Northern Territory (NT) Datalink (SA-NT, 2021), the Tasmanian Data Link Unit (TDLU, 2021) and the Victorian Data Linkages (VDL, 2021).

3.4.1 Data linkage in Western Australia

The Western Australian (WA) health system comprises both a public and a private sector. The Health Department of WA is responsible for overall management of health systems to ensure quality is maintained. The WA Data Linkage Branch (DLB) belongs to the Health Department of WA and is responsible for maintaining and development of WADLS, (Eitelhuber et al., 2018).

The systematic way of linking health record in WA started from the insights by Hobbs in the 1970s from his experience at Oxford. He was instrumental in suggesting a national medical record

linkage system and pushed for the implementation of a pilot study in WA (Hobbs & McCall, 1970). The initial project linked morbidity, mortality and health services back to 1966. Researchers from the Telethon Institute created the Maternal Child Health Research Database, which provided information about hospital mortality, birth defects and hospital inpatient morbidity. The research community was skeptical about confidentiality and privacy, and there was initially a lack of funding for the initiative (Holman et al., 2008). A window of opportunity came with a political change in the 1990s, which involved government and academic sectors collaborating and creating a sense of harmony and transcending boundaries. The skepticism regarding confidentiality and privacy was resolved with academic staff becoming involved with the data linkage unit (DLU).

As a result, the State Health Department became confident with the DLU, and became a principal funder, together with the academic sector (Holman et al., 2008). From 2000 onward, all administrative data have been backdated to 1966, with a master link key which is updated on a regular basis. Currently there are 100 million records, comprising over 50 linked datasets. New datasets are linked on a regular basis depending on the needs. Currently there are two separate datasets, one that has identity information and the other which has master keys, and information is extracted depending on needs (Eitelhuber et al., 2018).

Challenges still exist at many levels of data linkage in Australia. Australia has dual health systems, State and Federal, where under the Federal health system, data relating to aged care, claims to the national Pharmaceutical Benefits Scheme (PBS) and the Medicare Benefit Scheme (MBS) are held by the Australian Government. Initially this was a shortcoming for WADLS. However, in 2001, this shortcoming was resolved with a proper protocol designed for the study of diabetes. A pilot study to link data on death, PBS, and MBS in 148,000 patients with diabetes was approved, overcoming issues of privacy and confidentiality. The study has been successful and has led the Federal Government to approve the use of linked data from PBS, MBS and aged care backdated to 1990 and prospectively (Herman et al., 2008).

There have been over 1000 publications using these linked data from WADLS, which have impacted on health policy in the management of mental disorders, e.g. in preventing suicide (Brook et al., 2008). The WA data linkage has demonstrated that a data linkage system can provide infrastructure for health services research; but full state-wide support is fundamental to sustain it and challenges remain with cross-jurisdictional issues.

3.4.2 Centre for Health Record Linkage (CHeReL)

The Centre for Health Record Linkage (CHeReL) was established in 2006, for linkage of two Australian jurisdictions, the Australian Capital Territory (ACT) and New South Wales (NSW), both having separate government and health services. The estimate of resident population of ACT and NSW at the end of 2018 was 8.4 million, representing 33.6% of the Australian population (CHeReL, 2021).

Since 2006, CHeReL has used a Master Linkage Key (MLK) and probabilistic record linking techniques to link 198 million records (CHeReL, 2021). A summary of characteristics of data included in the CHeReL is shown in Table 3.3 (Irvine et al., 2019).

Table 3-3 Characteristics of data included in CHeReL Master Linkage Key

Characteristics of data included in the CHeReL Master Linkage Key at April 2019.				
Dataset and Jurisdiction	**Coverage**	**Number of records**	**Coverage**	**Frequency of update**
RBDM Birth registrations (NSW)	1994-2017	2,236,775	All births registered in NSW including the baby and parents	Annual
Perinatal Data Collection (NSW)	1994-2017	2,206,042	All births in NSW public and private hospitals including homebirths	Annual
Central Cancer Registry (NSW)	1972-2015	1,222,609	All incident cases of cancer in NSW	Annual
Pap Test Registry (NSW)	96/97-16/17	15,075,884	Cervical cancer screening test results for women residing in NSW at the time of test	Variable
BreastScreen NSW	1998-2016	6,122,103	All public breast screening mammography services for women aged 40 years and over in NSW	Variable
45 and Up Study (NSW)	n/a	266,887	A 10% sample of the NSW population aged 45 and over at recruitment	n/a
Ambulance NSW	2005-2018	9,888,755	All emergency and non-emergency cases responded to by NSW Ambulance	Quarterly
Admitted Patient (NSW)	2001-2018	46,137,250	All inpatient episodes from all NSW public and private hospitals	Six weekly
Emergency Department (NSW)	2005-2018	33,266,009	Presentations to emergency departments of public hospitals in NSW.	Six weekly

Mental Health Ambulatory (NSW)	2001-Jun 2018	41,391,832	People who are not inpatients of mental health units at the time of care	Six monthly
Perinatal Death (NSW)	1994-2015	11,876	All perinatal deaths occurring each year	Variable
RBDM death registrations (NSW)	1985-2018	1,571,752	All deaths registered in NSW	Six weekly
Cause of Death Unit Record File (NSW)	1985-2016	1,418,979	All deaths registered in NSW	Annual
BDM Birth registrations (ACT)	1997-Jun 2017	39,017	All births registered in ACT including the baby and parents	Annual
Perinatal Data Collection (ACT)	1997-2016	73,967	All births in Canberra Hospital, Calvary Public and homebirths	Annual
Kindergarten Health Check (ACT)	14/15-15/16	15,124	Children enrolled in the first year of full-time school in (ACT)	Annual
Cancer Registry (ACT)	1994-2015	31,478	All cases of cancer diagnosed in ACT	Annual
Cervical Screening Registry (ACT)	1994-2015	821,528	Cervical cancer screening test results	Variable
Admitted Patient Collection (ACT)	04/05-16/17	1,217,458	Inpatient separations from Canberra and Calvary Hospital	Annual
Emergency Department Data Collection (ACT)	05/06-16/17	1,387,223	All presentations to emergency departments of public hospitals in ACT	Annual
RBDM death registrations (ACT))	1997-Jun 2017	39,017	All deaths registered in ACT	Annual
Australian Early Development Census (Australia)	2009, 2012, 2015	859,521	Over 96% of children in their first year of full-time school in Australia	Three yearly
Australian and New Zealand Dialysis and Transplant Registry	1963-2016	681,317	Patients with end stage kidney disease receiving dialysis or renal replacement therapy in Australia and New Zealand	Annual

These linked datasets from CHeRel play a pivotal role in NSW in health policy, planning and research. The data are updated regularly between NSW and ACT with Master Linkage Keys. Over 130 datasets have been linked, used by 1,370 investigators in numerous projects. It attracted 70 million dollars in funding from the National Health Medical Research Council (NHMRC). There have been over 556 publications since its inception, including a wide array of health topics, including costs associated with chronic disease among children (Bell et al., 2020), prevalence of

intellectual disability in NSW (Carnemolla et al., 2020) and health care resource utilisation due to pertussis in adults in Australia (Leong et al., 2020).

There have been five published papers on SCI since the inception of the database in 2006. The first paper published on SCI was by Sharwood et al. (2017), which used linked databases from ambulance, deaths, and hospital records over a three-year period (2006-2009). Their study focused on improving health policy regarding transfer of patients from the initial injury site to a specialist spinal care unit. The study showed that delay in transferring a patient to the specialist SCI unit of more than 24 hours from the initial injury can result in 2.5 times the likelihood of developing secondary complications. These results are confirmed by previous population studies in the UK by Barr (2009) and in Canada by Wilson et al. (2016).

Three papers were related to costs involved: one related to cost associated with mental disorders in hospitalization was studied (Sharwood et al., 2020), while another focused-on epidemiology, cost and occupational context of SCI sustained while working for income in NSW, based on linked data from 2013-2016 (Sharwood et al., 2018). The third study reported discrepancies in funding in acute care versus funding received under the activity-based funding model based on linked data from 2013-2016 on all patients over 16 years (Vaikuntam et al., 2020). The fourth study included burden of mental illness and substance use and impact of health care response in patients with SCI from data collected during mid-2016 to mid-2019 in NSW (Sharwood et al., 2020). The study showed that those with preexisting mental illness and substance abuse were older patients, and SCI likely due to falls or self-harm. These cohorts had twice the length of stay and complications compared to patients without preexisting mental disorder (Sharwood et al., 2020).

There have been 518 publications since the establishment of CHeReL. While CHeReL has been successful since its inception, as evidenced by a vast array of publications across the board, challenges remain with data accuracy. An example is under-reporting of the number of indigenous women giving birth by in the Midwives Data Collection (MDC) and the Registry of Births, Deaths and Marriages (RBDM) in NSW. A study linking the MDC and RBDM over a 5-year period was able to improve the ascertainment of Aboriginal women giving birth in NSW (Xu et al., 2012). Ensuring the accuracy of data held in datasets is important for targeting of appropriate services during pregnancy and early childhood (Xu et al., 2012).

3.4.3 Centre for Victorian Data Linkage (CVDL)

The Centre for Victorian Data Linkage (CVDL) program, established in 2009, is another node of the Population Health Network Research, whose primary function is to link both health and non-health datasets within the Victorian jurisdiction. CVDL is located within the System Intelligence and Analytics Branch, Portfolio Strategy and Reforms Division within the Department of Human and Health Services (DHHS). Currently CVDL has a number of projects that provide researchers and policy makers with access to population information free of charge. It uses probabilistic methods and Master Linkage Keys to link the records and operates with guidelines strictly set by the Victorian Health Records Act 2001 and the Privacy and Data Protection Act 2014 (CVDL, 2021).

CVDL has a streamlined application process for cross-jurisdictional use. In 2018, the Commonwealth accreditation body approved CVDL to link sensitive Commonwealth data for studies of population health by researchers and clinicians as well as by health policy makers (CVDL, 2021).

CVDL links over 30 data sets within Victoria:

- Victorian Admitted Episodes Dataset (VAED) – all public, private and rehabilitation day centres provide minimum datasets on all patients who have used facilities
- Victorian Emergency Minimum Dataset (VEMD) – collects deidentified data for all patients who have been admitted to Victorian public hospitals.
- Victorian Cost Data Collection – an annual submission of all costs involved with patient admission in metropolitan and regional areas of Victoria
- Public mental health services – collects information on mental health services
- Alcohol and Drug Information System (AOD) –Services to AOD clients are linked to CVDL
- Victorian Integrated Non-Admitted Heath Dataset (VINAH) – includes non-admitted services such as specialist clinic, visits to outpatients, palliative care, post-acute care, subacute ambulatory care services, Victorian HIV services, family choice program
- Elective Surgery Information System – collection of elective surgery waiting lists in Victorian public hospitals
- Victorian Cancer Registry (VCR) – collection and provision of data for cancer
- Victorian Radiotherapy Minimum Dataset (VRMDS) – contains demographic and clinical information for admitted and non-admitted patients treated in Victoria
- Mental Health Community Support Services (MHCSS) – collection of services provided to severe mental illness and psychiatric disability during recovery process
- Family Services – collects data for the services provided to vulnerable young people and their families

- Family Violence Services – collects data for family violence related issues
- Sexual Assault Services (SAS) Victoria – collects data from people who have experienced sexual assault in the past and present, to provide support
- Disability Services Victoria – part of the National Disability Insurance Scheme (NDIS), contains data for those who are under 65 years old with permanent and significant disability
- Homelessness Services –data on services to prevent homelessness,
- Victorian Death Index – collection of registries of death
- Community Health – collection of services includes counselling, health promotion, medical and nursing, dental and allied health such as audiology, podiatry, dietetics, occupational therapy, physiotherapy and speech therapy
- Child Protection – record of services targeted to children and young people who are at risk of harm or whose families are unable to support them
- Public Housing Tenancies – Victorian government provides limited services to those who are low income
- Perinatal data collection (VPDC) – surveillance system for mothers and babies to help them with their health
- Home and Community Care (HACC) – for those 65 and younger who will receive services such as housework, personal care, meals, social support, allied health and home maintenance
- Early childhood intervention –specialized services for infants and young children with disability
- Births Registry Victoria – collection of registration of births in Victoria
- Public housing applications – collection of data for people who are applying for public and community housing applications
- Public Health Event Surveillance – used to assess and characterize the burden and distribution of adverse health events
- National Assessment Program: Literacy and Numeracy (NAPLAN) – tests skills such as reading and writing for every child during progress through school
- Australian Early Childhood Development Census (ADEC) – key findings of census in 2018.
- Intensive Care Registry – collection of patients who have been through intensive care units. Datasets are sent to Australian and New Zealand Intensive Care Society-Adult Patient Disease (ANZICS-APD) database
- Victorian State Trauma Registry (VSTR) – collects data from all trauma patients in hospitals in Victoria
- Victorian Cardiac Thoracic Registry (VCOR) – collects data from all patients with cardiac and thoracic conditions in Victoria

CVDL provided linked data to 150 health policy and planning projects, and there have been many publications. Some examples of publications from the linked data are:

- A longitudinal population study over 9 years (1st July, 2000 to 30th June, 2009) looking at the adverse outcomes associated with elective knee arthroscopy (Bohensky et al., 2013)
- Street et al. (2012) looked at the time spent in emergency departments by older patients living in residential aged care facilities in 2009. The study found that aged care patients represented 3.4% of all emergency hospitals and mean length of stay was 7.9 hours, compared to 4 hours for non-aged care patients. This has significant impact on costs associated with caring for aged care patients, alerting a new direction for health funding and health management for the hospital (Street et al., 2012).
- McQuilten et al. (2013) studied transfusion requirements and complications of red cell blood transfusion with patients with myelodysplasia (MDS) in Victorian hospitals from 1998-2008. The study found that there were 3,149 cases of MDS from 5.3 million people, which was a lot higher than the incidence of MDS registered with cancer registries. The study also found that there was more congestive heart failure among these patients than was recorded, but was not the main cause of death. This prompts the need for validation of the cancer registries (McQuilten et al., 2013).

3.4.4 South Australia and Northern Territory (SA-NT DataLink)

South Australia (SA) and Northern Territory (NT) DataLink was established in 2009 (SA-NT, 2021). Unlike in other States, SA-NT Datalink is not embedded in any government department, but governed by universities and research agencies. The funding for SA-NT Datalink comes from a consortium of financial members, which could provide flexibility but could also provide uncertainties both in funding and in the cost involved in delivering datasets to researchers (Schneider et al., 2019).

SA-NT DataLink uses the Privacy Act 1988 and provides a statistical data link service to researchers and policy makers. The “separation principle” pioneered by Michael Hobb (1980), also called the privacy protecting model, is used to separate personal identifying information from the content data by creating a specific linkage key. The data linkage unit is given data with a linkage key devoid of personal information. Only data custodians of SA-NT DataLink have access to patient information.

SA-NT DataLink links 50 sources, with over 57 million records on approximately 2.9 million individuals, providing deidentified datasets. Fees are charged to researchers for extracts of this data, with fees varying according to the size and number of datasets (Schneider et al., 2019). The

datasets are broadly divided into four categories: health, educational, social datasets, and registries. Details of each dataset can be seen in Appendix 3A-3C. Table 3.4 below shows names of the datasets, years, number of records and number of individuals covered.

Table 3-4 SA-NT: Names and record counts for data source

Dataset Name	Coverage	Number of Records	Number of Individuals
Health Data			
NT Client Master Index	1991-2017	4,224,874	854,222
NT Perinatal (Trends) - by baby	1986-2016	108,731	108,689
NT Perinatal (Trends) - by mother	1986-2016	104,754	62,837
NT Inpatient Activity	2000-2017	242,693	201,167
NT Primary Health Care Collection	2008-2017	94,557	73,743
NT Emergency	2000-2017	438,140	316,028
NT Public Hospital Pharmacy	2006-2014	Internally linked by NT Department of Health to its Client Master Index	
NT Hearing Health Data Collection	2008-2016	18,898	18,849
SA Public Hospital Separations	2001-2018	7,112,477	1,404,479
SA Public Hospital Emergency Dept.	2003-2018	7,155,765	1,614,773
SA Dental Service (Titanium)	1999-2015	780,226	580,503
SA Perinatal (linked by baby)	1986-2016	1,985,080	600,297
SA Perinatal (linked by mother)	1986-2016	1,662,645	315,554
SA Historic Cause of Death	1989-2005	195,930	195,930
SA Child Health Check	2005-2017	304,978	303,668
SA Mental Health - Metro	1996-2017	625,550	258,652
SA Mental Health - Country	2006-2015	128,265	128,265
SA Drug and Alcohol Services	2002-2016	47,631	Not yet linked
Breast Screen SA	2001-2018	384,453	339,015
SA Cervical Screening	1993-2017	8,745,360	799,829
Education Data			
NT Student Activity	2004-2018	474,863	96,272
NT NAPLAN (Public Schools)	2008-2018	79,537	41,369
NT Preschool	2005-2018	47,031	35,178
NT NAPLAN (Catholic and Christian)	2008-2018	19,583	11,888
SA Public School Enrolments Census	2004-2017	3,287,326	624,173
SA NAPLAN	2008-2017		
SA Running Records	2008-2017	Internally linked by SA Department of Education	
SA English as an Additional Language	2005-2017		
SA Preschool	2009, 2012, 2015		
Australian Early Develop. Census	2009-2015	1,128,891	859,245
Registries			
NT Birth Registry	1868-2018	184,201	183,965
NT Death Registry	1870-2017	55,322	53,702
NT Immunisation Register	1995-2018	436,443	288,031
NT Rheumatic Heart Disease Register	1997-2017	4,078	4,078
NT Cancer Registry	1991-2015	14,081	13,144
SA Birth Registry (linked by baby)	1944-2019	1,498,252	1,427,152
SA Birth Registry (linked by mother)	1944-2019	2,599,835	1,065,295
SA Birth Registry (linked by father)	1944-2019	1,412,449	1,102,352

SA Death Registry	1990-2019	960,103	342,511
Codified Cause of Death SA	2006-2017	118,495	118,495
Codified Cause of Death NT	2006-2017	8,066	8,066
Coronial Codified Cause of Death SA	2006-2017	23,024	23,024
Coronial Codified Cause of Death NT	2006-2017	3,315	3,315
ANZData Registry (for renal transplant or renal replacement therapy)	1963-2017	1,335,405	67,217
SA Cancer Registry	1990-2016	497,116	214,958
Social Data			
NT Child Protection	1998-2018	38,801	37,089
NT Integrated Justice Information System (Adults)	1997-2018	115,260	10,319
NT Integrated Justice Information System (Juveniles)	1997-2018	Not linked	Not linked
NT Public Housing (Urban)	1991-2014	42,523	26,395
SA Child Protection	1991-2017	587,575	213,276
SA Electoral Roll	2009, 2013, 2017	3,380,007	1,390,983
SA Youth Justice	1994-2016	14,710	13,827
SA Homeless to Home	2011-2017	638,690	89,811
Housing SA	1987-2017	3,926,272	1,020,660

There have been 73 published articles from the SA-NT Datalink registry. Health administrative records have been able to provide insight into the prevalence of comorbidities among Aboriginals, who were likely to have three times more risk factors influencing cancer survival when compared with non-Aboriginals (Banham et al., 2018).

The quality of data linkage from SA-NT DataLink was evaluated in 2020. The study showed there was a 99.6% accuracy with linkage with upper bound of 95% confidence whereas false negative, missed link was 0.8% (SA-NT Datalink-Quality Assurance, 2020).

3.4.5 Tasmanian Data Linkage Unit (TDLU)

The Tasmanian Data Linkage Unit (TDLU) was established in 2010, collaborating with the Department of Health and Human Services (DHHS) as the lead agency with the Menzies Research Institute of Tasmania as the operational unit. The TDLU uses probabilistic linking methods to link de-identified data from a range of sectors, including health, education and welfare, providing information to researchers and policy makers in Tasmania (Stokes et al., 2019).

The TDLU is nationally funded by the Population Health Research Network (PHRN), strictly following the Commonwealth Privacy Act 1988, regulated by the Right to Information Act 2009 and Personal Information Protection 2004 (Stokes et al., 2019).

Since inception, TLDU has linked over 65 individual datasets representing over 8-million-unit records covering a population of 1.8 million in Tasmania. Twelve datasets have been linked and are available for research:

Table 3-5 Summary of core datasets linked in TLDU

Dataset	Date Range	Total Records	Unique Keys
Public Hospital Admitted Patient Episodes	2007 –2017	1,356,100	329,800
Public Hospital Emergency Department Presentations	2000 –2017	2,234,000	543,500
Deaths Registry Tasmania	1970 –2018	186,400	186,100
Births Registry Tasmania	2000 –2018	113,900	113,500
Tasmanian Cancer Registry	1982 –2016	102,400	88,400
Perinatal Data Collection – Mother (Public & Private)	2005 –2015	67,300	42,200
Perinatal Data Collection – Child (Public & Private)	2005 –2014	61,600	61,600
Australian Early Development Census (AEDC)	2009, 2012, 2015	855,800	855,000
Ambulance Tasmania Emergency Incidents	2010 –2015	321,500	151,000
Tasmanian Community Mental Health Data Collection	2000 - 2015	1,375,100	35,400

TDLU has been slow in starting as it took over two and a half years to get the infrastructure in place. However, with thorough planning and a proper infrastructure and funding from the government, it is looking promising. For example, the current project, ‘Pathways To Better Education Outcome For Tasmania’s Children’, requires 14 datasets to be linked. The research is designed to obtain insights into early childhood health and education services for children in Tasmania. The project is a collaboration between the Tasmanian government, Telethon Kids Institute and the University of Western Australia.

3.5 Gaps in CDL in Australia with SCI

Even though Australia is advanced in data linkage, there is no national database dedicated to SCI, although SCI data are captured in the trauma database and information on adults with SCI are captured by the Australian Spinal Cord Injury Register.

Currently Australian health information relating to SCI is fragmented. There are multiple data custodians involved in collecting information for their own purposes. To obtain a good picture of the life cycle of health information generated by a person with SCI, all information should be linked as accurately as possible and the data should be of high quality.

Fragmentation of health information exists in the following areas:

- Hospital admissions – these can be divided into acute and chronic; at present not all the hospital data are linked; patients may be treated in different hospitals so that it is difficult to obtain a full picture of clinical information;
- Rehabilitation – patients undergo lengthy rehabilitation at various centres, but none of this information is linked, so there is no repository of the types of interventions patients have had;
- Pharmacies and alternative medicine: Patients with SCI are dependent on a range of medications, but there are no central records held;
- Allied health professionals: data regarding patients' visits to allied health professionals such as physiotherapists, occupational therapists, psychologists and orthotists are not linked;
- Primary health providers: patients are referred to primary health providers on discharge from hospital and their visits should be linked;
- Social welfare: many patients with SCI are reliant on social welfare to assist with travel, social support and a range of financial reasons;
- Administrative data: various government stakeholders, as well as financial stakeholders, own clinical information about SCI.

Patients with SCI are unique and challenging in that despite their significant disability, their average life span is about 40 years. Throughout their lifespan, these patients undergo lengthy rehabilitation, have frequent visits to hospitals because of associated secondary conditions, and are heavily reliant on medical interventions, as well as being dependent on social welfare (Gabbe et al., 2016; Norman et al., 2010; Norton, 2010; M. Wyndaele & J. J. Wyndaele, 2006). Thus, they

generate a large set of medical data in both public (Commonwealth, State and Community) and private sectors. Hence, capturing all information associated with such patients is challenging. In addition, patients may attend different hospitals, not necessarily confined to one geographical area. There is a recent trend of patients with SCI moving to different states, which makes it difficult to gather information about them into one comprehensive information source (ABS, 2011; AIHW, 2019). These distributed data are difficult to identify and key information may not be available to clinicians or to patients at the right time and place, as clinical data are kept in different databases (Banfield et al., 2013; Pang & Hansen, 2006).

Understanding how the Australian health information system works is vital in order to appreciate (a) what needs to be linked and why, (b) how data are collected, coded, stored and managed, (c) who should own the data, and (d) where it should be stored.

3.5.1 Data collection regarding SCI

The Australian Spinal Cord Injury Register (ASCIR) is a national database established by the Australian Institute of Health and Welfare (AIHW) in 1995, and is managed by the National Injury Surveillance Unit (NISU) at Flinders University. The AIHW is the data custodian for ASCIR. The rationale for this registry is to produce annual epidemiological information on the incidence of SCI in Australia from the six specialised spinal units (NISU, 2021).

There are six specialist spinal units for SCI in Australia (Table 3.6). ASCIR is an opt-in system, where each individual unit is responsible for providing the minimum dataset to the registry.

Table 3-6 Australian Specialist SCI Units

Specialist Spinal Cord Injury Units	**Hospital Location**
South Australia	South Australian Spinal Cord Injury Service – Royal Adelaide Hospital
Queensland	Queensland Spinal Cord Injuries Service – Princess Alexandra Hospital Brisbane
Western Australia	Sir George Bedbrook Spinal Unit – Royal Perth Hospital, Perth
Victoria	Victorian Spinal Cord Service – Austin Hospital Melbourne
New South Wales (NSW) – 2 locations.	Prince of Wales Hospital Spinal Cord Injury Service Sydney, and Royal North Shore Hospital Spinal Cord Injury Service Sydney

Information about incidence of SCI in the Northern Territory will be reported through the South Australian Spinal Cord Injury Service. In Victoria, most patients with SCI who will have been

admitted to Trauma Centres, either the Alfred or the Royal Melbourne Hospitals, will be then be transferred to the Victorian Spinal Cord Service at the Austin Hospital.

There is a range of data custodians involved along the journey of SCI. The following section shows the range of data custodians involved and the roles they play, as well as some of the issues involved in CDL.

3.5.2 Multiple data custodians for SCI

Figure 3.3 illustrates the distributed health information and multiple data custodians involved with patients with SCI. The data custodians can be divided broadly into three categories:

- Clinical data custodians (Emergency Departments, Intensive Care Units, General Practitioners, Pharmacy and Rehabilitation (including physiotherapists, occupational therapists),
- Statutory data custodians (Government and research institutions), and
- Financial data custodians (health insurance companies)

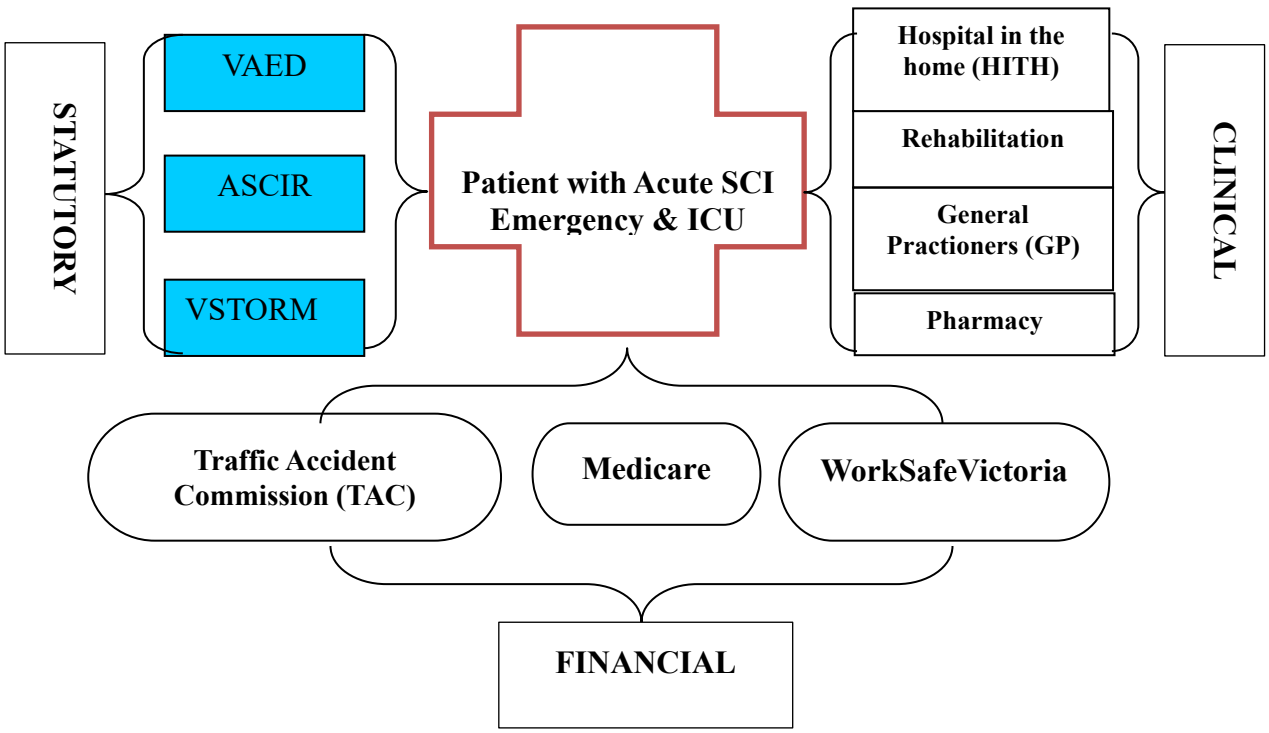


Figure 3-3 Multiple Data Custodians

VAED: Victorian Admitted Episode Datasets; ASCIR: Australian Spinal Cord Injury Register;VSTORM: Victorian State Trauma Outcomes Registry Monitoring Group; HITH: Hospital in the Home; GP: General Practitioner; TAC: Transport Accident Commission

The roles of each data custodian are explained below:

Information flow to Clinical Data Custodians

A patient would be admitted to hospital via the Emergency Department after injury, where the initial assessment would be done. The data are coded by the ICD-10-AM version (ICD, 2021) and the information stored in the Victorian Emergency Minimum Dataset (VEMD) database (VEMD, 2021). Within the acute hospital, a patient's clinical information is shared by clinicians in the hospital and Hospital in the Home (HITH) (Caplan et al., 2012; Caplan, 2013). This information is also provided electronically on a regular basis to statutory bodies such as the Victorian Admitted Episodes Datasets (VAED, 2021), the Australian Spinal Cord Injury Register (ASCIR, 2016), and the Victorian State Trauma Outcomes Registry Monitoring Group (VSTORM, 2021), which also includes data from the Victorian Ambulance Service database. In the case of road traffic accidents, the patient information is sent to the Traffic Accident Commission (TAC), which insures and provides case management for people with traumatic SCI (TAC, 2021). In the case of a work-related injury, data are provided to WorkSafe Victoria.

Often with higher-level injuries such as functional cervical injury C-1 to C-4, a patient would be admitted to the Intensive Care Unit (ICU), especially if ventilator support is required (VEMD, 2021). Clinical information obtained in ICU is provided to the Australian New Zealand Intensive Care Unit Society, Adult Patient Database (ANZICS-APD), a dedicated database for patients who have been admitted to ICU (ANZICS, 2021). After discharge from ICU, the patient may return to the acute ward and then undergo a lengthy rehabilitation process, initially close to the acute hospital, then later closer to home (RTRC, 2021).

After discharge from the hospital, a patient would visit a General Practitioner (GP) for ongoing management and may be referred back to hospital for treatment of a range of complications (DeJong et al., 2013). Among recurrent conditions, urinary tract infections, pressure ulcers, skin problems, depression and sleep apnoea are some of the common sequelae of SCI (Cripps & Harrison, 2008; Silver, 2011; Thietje et al., 2011). Blood is often taken for testing and monitoring because of infections (Cohen & Novick, 2013). Hence, in addition to clinical information from the emergency department (VEMD) and ICU (ANZICS-APD) datasets, there is also a large set of clinical information from pathology. Patients with SCI also experience problems with blood pressure, and their ability to control temperature, and sweating (Guilcher et al., 2013; Jacobs &

Nguyen, 2013). Because patients with SCI require a number of regular medications to control blood pressure, muscle spasms, anxiety and depression, and pain, a large database of information about a patient's medication history will be stored by pharmacists (Steuer et al., 2013; VN1, 2021). Depression and alcohol dependency will often lead to patients needing regular sessions with a psychologist (Paker et al., 2013; Ullrich et al., 2014).

The clinical results from pathology would stay within the Laboratory Information System, and X-rays and pharmaceutical information would stay within the hospital Information System (HIS). Thus, the acute hospital would have at least four different databases with relevant patient information (Figure 3.4);

- Emergency (VEMD),
- Radiology as part of the Hospital Information System (Medtrack/Cerner),
- Pathology, which has an independent Laboratory Information System called Kestral, which sits within Cerner, and
- Pharmacy, which sits within the Hospital Information System (Cerner)
- Patients admitted to ICU ANZICS-APD.

Therefore, within the acute hospital, there are five independent repositories where patient data are stored.

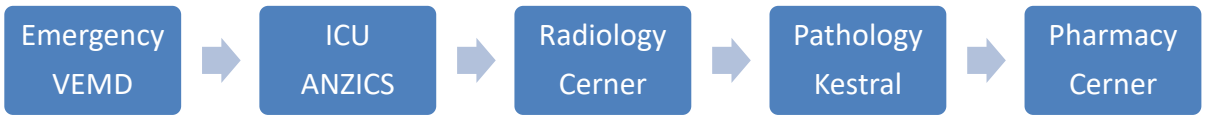


Figure 3-4 Acute Hospital: Databases

Information Flow to Financial Data Custodians

Health funds are another group of data custodian maintaining large volumes of patient health records through payment systems.

The Australian health system has both public (Medicare) and private systems (private insurance companies). Both the private and the public sector use ICD-10-AM codes for all patients and report to the Department of Health and Human Services. As previously stated, injuries sustained

at work in Victoria are covered by WorkSafe. Transport-related injuries are managed by the Transport Accident Commission (TAC, 2021).

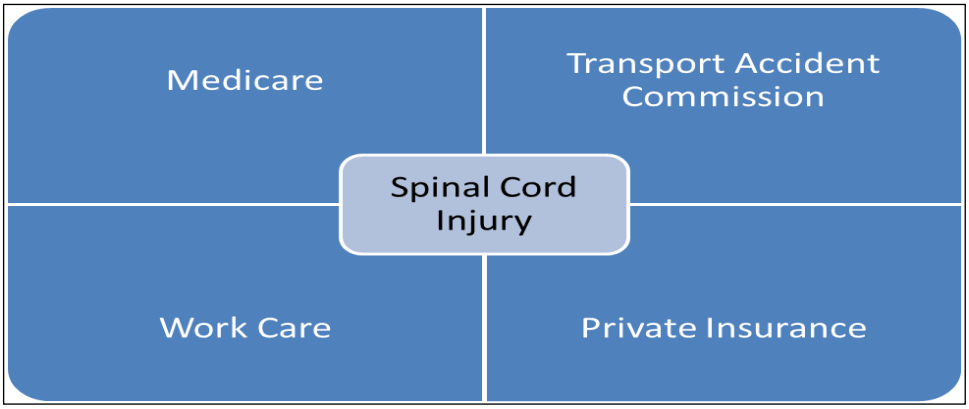


Figure 3-5 Health Funding Data Custodians

The four health funding custodians are shown in Figure 3.5. Health funding data custodians are independent of each other.

Medicare is one of the major health funding custodians of patients with SCI. These patients would use either Medicare or private insurance companies to cover their medical expenses. Medicare Australia is an Australian Government agency delivering a range of payments and services to the Australian community. It is a prescribed agency under the *Financial Management and Accountability Act 1997* and is a statutory agency under the *Public Service Act 1999* (Medicare, 2021). Most Australians contribute 1.5% of their taxable income to the Medicare levy.

Private insurance companies are another group of financial data custodian which hold a huge store of details on patient claims. A 2009 study showed that 51% of the Australian population had some form of private health insurance (Shamsullah, 2011) because the Australian taxation system encourages those on middle to high incomes to take out private health insurance. There are numerous private insurance companies such as HBF, Medibank, Australian Health, Teachers Union and QBE which would hold information about claims made by patients with SCI.

The Transport Accident Commission (TAC) covers the medical expenses of people involved in transport-related accidents. The TAC reported that 46% of the total number of injuries resulting from road traffic accidents were SCI in the period 2017-2018 (TAC, 2021).

While injuries relating to work are reported to WorkSafe, major claims for SCI for both WorkSafe and TAC are managed by TAC's major injury team (WorkSafeVictoria, 2021).

Table 3-7 Comparison of claims in the 3 years 2008-2011

Claims	2008-2009	2009-2010	2010-2011
Claims/1000 workers	10.8	9.98	10.58
Fatalities	27	<16	26

Source: (WorkSafeVictoria, 2021)

The four health funding custodians are independent of each other and do not coordinate their data. They collect patient information for payment purposes as well as for health and safety and education (WorkSafeVictoria, 2021).

Information Flow to Statutory Custodians

As shown in Figure 3.6, the Australian and Victorian governments collect information about patients with SCI on a regular basis from hospitals and rehabilitation centres and pass them to the Australian Spinal Cord Injury Register (ASCIR), the Victorian Admitted Episodes Dataset (VAED), and the Victorian State Trauma Outcomes Registry (VSTORM). These agencies are independent of each other and there is no health information flow between them.

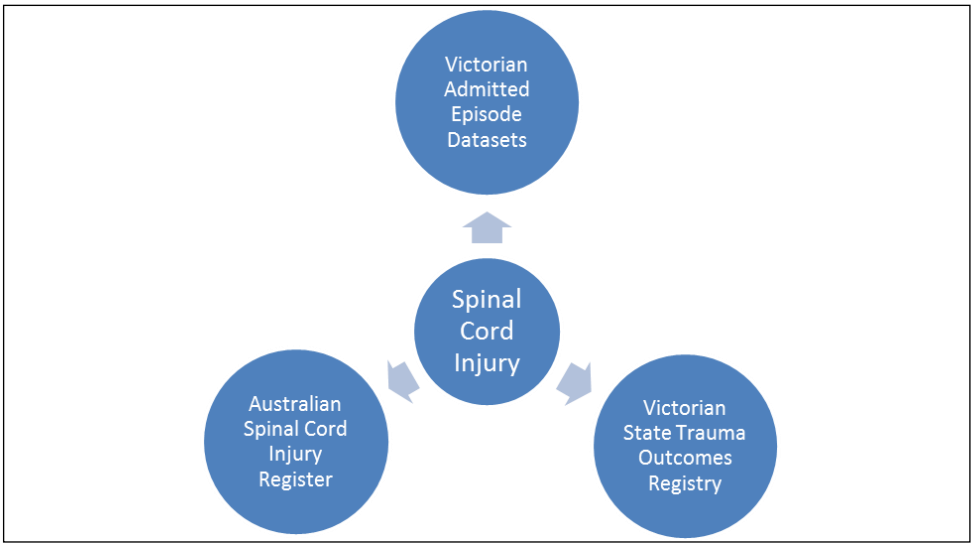


Figure 3-6 Statutory Data Custodians

The Victorian Admitted Episodes Data Set (VAED) collects morbidity data on all admitted patients from Victorian public and private acute hospitals, as well as rehabilitation centres, extended care facilities and day procedure centres (VAED, 2021). The information collected is used for planning of health services, policy formulation, casemix funding and epidemiological research (VAED, 2021).

The Victorian State Trauma Outcomes Registry (VSTORM, 2021) is commissioned by the Department of Health and Human Services in collaboration with the TAC to reduce preventable deaths. Changes to systems of care are monitored to ensure that outcomes are improving, including reduction in deaths and disability over time. The registry collects trauma-related information from both metropolitan and regional areas (138 hospitals) statewide (VSTORM, 2021).

3.6 What are the issues with CDL in SCI?

Information about patients with acute SCI is kept in many different places by a range of data custodians, as discussed above. The current Australian Health Information System is not well enough coordinated to provide a systematic approach to support clinicians or to satisfy information needs of consumers (Matter et al., 2009; Moon, 2014). Each data custodian will maintain necessary information for their record keeping, but it is not easy to access all the information necessary to obtain the complete history for any one person. Even though Australia is leading in data linkage through WADLS for example, there is no national data linkage system like those of the UK or Canada. Certainly, there is no national system to link health data over the life span of a person with SCI.

There are many challenges for effective CDL:

- ensuring quality of data
- protecting privacy and security of data
- Human Research Ethics approval.

3.6.1 Data Duplication and Inconsistencies – data quality

Problems exist when providers duplicate patient data in unlinked systems without regular updating, e.g., when a patient's history, rehabilitation, drug chart or allergy information is stored in an autonomous database and is not updated into a single database automatically. It presents huge discrepancies when a patient's details are updated in one system and not another.

Lack of standardization of information makes it difficult to merge databases between hospitals.

In Victoria, before trauma centres were established, all patients with SCI were taken to the specialist Spinal Unit at the Austin Hospital and surgery to stabilize the spine was performed there. However, when the trauma centres were established, most patients with SCI were taken to one of those centres first, had their surgery, and were then transferred to the Spinal Unit for ongoing care and rehabilitation.

Trying to track down patient medical records from one hospital to another is a challenge, as different unique identifiers are used by each site. Not all health administrators are trained in the same way and not all are aware of the standardized coding scheme that is used in major hospitals in Victoria (ICD, 2021). Many patients spend a long period in rehabilitation centres where there are limited health information services, making it difficult to merge datasets with those of the major hospitals (Moon et al., 2014). Funding bodies may record consultations but not the reason for the service.

The success of CDL relies on the quality of the datasets. Understanding data linkage methods is essential for any clinical data linkage project, as different techniques have different limitations. Choosing the correct linkage method is important and will depend on an understanding of datasets. How data are collected and in what format datasets are stored will also determine the appropriate data linkage method. For instance, some datasets from hospitals might be unstructured, in that there may be duplications and redundancies. Hence analysis without the pre-processing of data will yield incorrect results and could lead to incorrect predictions. This process is called ‘data cleaning’ in a generic sense or ‘normalization’ in technical terms (El-Sofany, Ghaleb, & El-Seoud, 2010). The process of normalization depends on how the data are collected. The data cleaning or normalization process should eliminate duplication and improve accuracy, thereby improving efficiency.

3.6.2 Privacy and Confidentiality

Generally, the public are concerned about their information being linked and shared between other parties, often without their knowledge. Whilst linking data is good for research, crime (especially fraud) detection and taxation, it could be subject to being abused by commercial data mining, especially by companies that have no relevant regulations. There is a need, therefore, for a fine balance between having the right information for the right people at the right time and securing the privacy and confidentiality of the individual.

All data released by Australian data linkage sites are required to have ethics clearance certifying that the request meets the Human Research Ethics Committee guidelines (HREC, 2021). Individual information is not released to researchers, but is provided as a record ID with Linkage ID and is strictly accessed only by authorized persons. The regular updates sent from various data custodians are done by using statistical probability methods (PHRN, 2021).

Privacy Preserving Record Linkage technique (PPRL) is used in data linkage by WADLS (WADLS, 2021). PPRL is commonly used in big data linkage to link datasets held in many different places that belong to the same person, without revealing sensitive information. PPRL in big data poses many challenges in scalability to multiple datasets, quality assurance, and ensuring privacy (Vatsalan et al., 2017). WADLS datasets are dynamic in that datalinks are created, modified and deleted on a regular basis. However, caution is needed, as this process might violate security, and confidentiality and compromise data quality if not managed properly.

CDL may have a number of benefits, including cost savings from better understanding of disease, and better health outcomes from the research. The main risk is compromising privacy. The problem with these health administrative data is that they are collected for the purpose of administration and quality assurance but without patients' consent. Under the Privacy Act 1988, waiver of individual consent is approved if a project is deemed to be of public interest and provided the data custodian is responsible for confidentiality. However, actually maintaining confidentially is still an issue. In order to maintain confidentiality, the 'separation technique', where patient demographics are separated from clinical information, is used. This way, data linkage units do not see clinical information and the researchers do not see patient demographics (DLWA, 2021).

Protecting privacy and confidentiality can delay the release of the linked data and at times can be costly. Initially the datasets from the Ontario Cancer Data Linkage Project were available for physicians and to a handful of local researchers. However, the cancer data, called 'cd-link', has been opened to a broader community so as to attract more researchers to share the knowledge (Earle, 2014).

3.6.3 Human Research Ethics Committee (HREC) and Timelines

In Australia, data collection is done at many levels, with different jurisdictions responsible for different data collections. Unlike the situation in the UK and New Zealand (Palamuthusingam et al., 2019), there is no complete ownership of national data in Australia. The lack of streamlined processes makes obtaining ethics approval extremely difficult when researchers seek to obtain

ethics clearance from a different jurisdiction. Andrew et al. (2016) described the burdensome process of linking three databases: Australian Stroke Clinical Registry (AuSCR), the National Death Index and state-held hospital data (Victoria, Western Australia and Queensland), where receiving data from multiple jurisdictions took three years (Andrew et al., 2016).

To expedite the judicial process, the National Mutual Acceptance Memorandum of Understanding (NMA MOU) was established to improve the complicated ethics process. This, however, does not work nationally. NMA works for sites within Victoria, but New South Wales, ACT and Western Australia prevent data linkage with NMA, which can cause confusion and delay in getting results. Different interpretations of NMA MOU create confusion and delays in research, which need to be rectified (Palamuthusingam et al., 2019).

3.7 Future Research Directions of CDL in Australia

The benefits of clinical data linkage have been widely recognized by the Government and researchers in Australia, and various initiatives have been commenced to improve the current system. At a Federal level, My Health Record, which has superseded the Personally Controlled Electronic Health Record (PCEHR), has been trialed. At the State level, in Victoria, a prospective data collection system in patients with SCI (SpinalCARE) has been initiated.

3.7.1 My Health Record (MHR)

The Australian Government has tried to build infrastructure that captures all patient-related data into one source and that can be controlled by patients. In 2012, recognizing the importance of clinical data linkage in providing the full extent of the costs and burden of injury, the Australian Government invested $800 million dollars to reform eHealth through an initiative called the National E-Health Transition Authority (NEHTA) (NEHTA, 2016). The project was formerly called the Personally Controlled Electronic Health Record (PCEHR), now superseded by My Health Record (MHR). PCEHR was an opt-in system; there was a lot of challenges in that there was distrust of computer systems in general and concerns about security, and uptake by the general population was very low (Hambleton & Aloizos, 2019). The system was reviewed and obstacles were identified and in 2015 PCEHR was renamed My Health Record to include richer content, ease of use, and an opt-out system. Now all Australians have an MHR unless they choose not to. The patient can control the content and the entities with whom the information is shared (MHR, 2021).

Currently, the Australian MHR is in its infancy; it only links adult patients' visits to doctors via a health identifier number, and does not provide diagnoses or results of treatment. It has the potential to include medical diagnosis, pathology results and pharmacy results to support both clinicians and patients in achieving better services (NEHTA, 2016). The system has huge potential to provide support for all patients and clinicians. While this may be a valuable start to collating information for SCI patients, developers of the MHR need to be aware of the problems that this particular condition presents and the data required for successful treatment (da Silva et al., 2012; Exeter et al., 2014).

3.7.2 SpinalCARE

At a State level, a prospective database, SpinalCARE has been commenced to capture clinical details of all cases of SCI in the Victorian Spinal Cord Service (VSCS) (Austin Health, 2021) developed by VSCS and the Institute for Breathing and Sleep (IBAS). and integrating data collection within routine clinical practice (VSCS, 2021). This system will provide flexibility and valuable epidemiological information about patients with SCI, for research and quality improvement programs as well as international collaborations (SpinalCARE, 2021). Prior to this, the VSCS had no electronic register for patients and sent a limited amount of information to the ASCIR.

3.8 **Conclusion**

Using SCI as an example, it is clear that there are multiple heterogeneous data custodians and a lack of coordination between them. A more efficient infrastructure is required, one that will embrace long term care of patients with chronic conditions, and the Australian health system has to address these issues.

Relevant best practices of English-speaking countries that have effective health information systems – Australia, Canada, Scotland and Wales - have been discussed. The research shows that, for a range of reasons, not all countries are able to emulate these systems, as they are dependent on health infrastructure, and active participation from the government and regulatory bodies. In Australia, various national initiatives, e.g. My Health Record, provide potential solutions to improve the fragmented systems which are some of the barriers to CDL. Whilst the advantages of CDL are well known, there are still challenges involved.

The next chapter discusses methods involved in clinical data linkage of patients with acute SCI in three hospitals.

Chapter 4

Methods:
Retrospective Time Series Analysis (TSA)

4 METHODS: RETROSPECTIVE TIME SERIES ANALYSIS (TSA)

4.1 Retrospective Time Series Analysis

This phase forms the major part of the thesis and involves a retrospective study linking health administrative data sets of spinal cord injured patients. Retrospective studies are not uncommon in medicine when looking for trends of diseases or patterns. Time series analysis (TSA) is concerned with changes over time, e.g., weekly, monthly, quarterly, annually, looking for patterns over time with the intention of forecasting. This method is used in business for analysis of stock prices, inflation and unemployment indices, monthly sales and currency cross rates.

TSA is used as a tool in many areas of medicine. This approach was used in the investigation of causes of diabetes (Harris et al., 2010) and risk factors in colorectal cancer (Morris et al., 2013). In this case, time series analysis was undertaken to quantify trends in healthcare utilization over time. Other uses of TSA have been in the public health arena, for example, to control diarrhea during an outbreak of Shiga toxin-producing E. coli (Bernard et al., 2014), studying the impact of bronchiolitis on emergency department resource use and cost (Akenroye et al., 2014), the impact of alcohol and road traffic policies in Botswana over 2004-2011 (Sebego et al., 2014) and the effects of weather on daily admissions to hospital due to asthma in Shanghai (Zhang et al., 2014).

For this study, TSA was used as a main tool to understand the pattern of spinal cord injury (SCI) admissions and as a predictive model for chronic disease. Two time series analyses were undertaken for the study. The first was a pilot study using data from Austin Health, the location of the Victorian Spinal Cord Service and the specialist centre for traumatic SCI in Victoria. The second study involved linking the Austin Health data with those from the two acute trauma services for adults in Victoria using the appropriate data linkage methods. The results of these time series analyses are reported in Chapters 5 and 6.

4.2 Ethical considerations: Quality Assurance

Ethics clearance was obtained from three major hospitals in Victoria as well as from the University of Melbourne:

- Austin Health Human Research Ethics Committee, Project no.: EER H2011/04539
- Melbourne Health Human Research Ethics Committee, Project no.: 2015.169 HREC/15/MH/229
- Alfred Health Human Research Ethics Committee, Project no.: 566/15

- University of Melbourne: Project no.: 1237523.2

The datasets released from the three major hospitals of this study have been subject to ethics clearance and have met the guidelines of HREC. These datasets are deidentified. The individual key has been created to link within the three hospitals. Details of each ethics clearance can be seen in Appendices 1A, 1B, 1C & 1D.

4.3 Trauma Centres

The Victorian State Trauma System was established in 2000 to reduce morbidity and mortality from trauma by improving trauma management. Victoria has two major adult trauma centres (The Alfred and the Royal Melbourne Hospitals) and one paediatric hospital (The Royal Children's Hospital) that are located in metropolitan areas but provide statewide services. There are five rural Departments of Health and Human Services that provide urgent and primary care services to regional areas according to trauma triage guidelines to ensure appropriate services are provided (VSTR, 2018).

In addition, three metropolitan health services (Austin Health, St. Vincent's Hospital and Monash Medical Centre) provide neurosurgical services, each providing specialist trauma care. Austin Health is the headquarters of the Victorian Spinal Cord Services, which is one of six specialist Spinal Cord Injury Services in Australia, and provides services for people with acute and non-acute SCI in Victoria, Tasmania and the Riverina region of New South Wales. Austin Health serves as a funnel for patients admitted from either the Alfred or Royal Melbourne Hospitals for SCI rehabilitation (Austin Health, 2018). Once patients are discharged from these acute hospitals, the majority of them are moved to a rehabilitation hospital for extensive treatment (RTRC, 2018).

The incidence of major trauma in Australia declined significantly from the middle of the 1970s to the 1990s after the introduction of mandatory seat belts while driving (McDermott and Hough, 1979, Mullins, 1999), wearing helmets, random alcohol blood testing and speed cameras, which have substantially reduced road trauma.

The Victorian State Government established a taskforce to review trauma and emergency services: 'The right patients to the right hospital in the shortest time" (Atkin et al., 2005). As a result, the Victorian State Trauma System (VSTS) was established in 2000, jointly funded by the Victorian Government and the Transport Accident Commission, with its main role to facilitate the management and treatment of major trauma patients in Victoria (VSTS, 2021). This included the

designation of the Alfred Hospital (Alfred Health) and the Royal Melbourne Hospital (Melbourne Health) as adult trauma centres. The success of the system relies on the quality of data collection and analysis.

A statewide major trauma database, the Victorian State Trauma Registry (VSTR) was established, which collects data from 138 health services to monitor quality of service and patient survival over time, and to compare outcomes between patient groups (VSTR, 2021). This information is used to monitor and assess each component of Victorian State Trauma System to facilitate further enhancement. While the service is stable, there are still challenges in delivering quality services to the booming Victorian population, which is increasing at a rate of 100,000 per year. The annual report of the VSTR shows that in the period 2014-2015, SCI accounted for 7% of total admissions. These patients are transferred from the trauma centres to the Victorian Spinal Cord Service (Austin Health, 2021).

4.4 Data Collection Methods

The data for the initial Austin Pilot study came from the Victorian Admitted Episodes Dataset (VAED) and Intensive Care Units database (ICU) from mid-1998 to mid-2008.

The primary data sources for the major cohort study have come from adult patients with SCI who were admitted through the Emergency Departments and Intensive Care Units of the Alfred, Austin, and Royal Melbourne Hospitals from 1st July, 2000 to 30th June, 2014. Data sets were derived from clinical care records or abstracted from Quality Assurance or casemix data related to those patients.

A hospital discharge is the formal release of a patient from a hospital after a procedure or course of treatment. A discharge occurs whenever a patient leaves because of finalization of treatment, signs out against medical advice, transfers to another health care institution or on death. A discharge can refer to in-patients or day cases. Transfer to another department within the same institution is excluded.

Discharge by diagnosis is referring to the principal diagnosis, i.e., the main condition diagnosed at the end of the hospitalization (in-patients) or day treatment (day cases). The main condition is the one primarily responsible for the patient's need for treatment or investigation (ICD, volume 2).

Datasets used for the project were already coded by the Health Informaticians at the respective hospitals at the time of discharge according to the latest International Classification of Diseases, 10th revision (ICD-10AM) criteria, or by the Intensive Care Units or the Victorian Spinal Cord Service.

The characteristics of the three datasets are described below:

4.4.1 Victorian Admitted Episodes Dataset (VAED)

The Victorian Admitted Episodes Dataset (VAED) comprises demographic, clinical and administrative details for every admitted episode of care occurring in Victorian hospitals, rehabilitation centres, extended care facilities and day procedure centres. Each patient is denoted by a unique hospital identifier code. A person with SCI may have multiple acute and rehabilitation admissions in different health services for the same injury.

The VAED is compiled according to financial years (July to June). Hospitals submit data files to Datacom, a facilities manager contracted by the Victorian Department of Health and Human Services to process the data files. On the 10th of each month, Datacom sends a year-to-date data extract to the Department, which constructs VAED files from this extract (VAED, 2021).

4.4.2 Victorian Emergency Medical Database (VEMD)

The VEMD includes hospital episodes data, which contain patient demographics and conditions during hospital admission. The important aspects of the data are the Diagnostic Related Groups (DRG) and the data coding according to the ICD-10AM.

4.4.3 Australia New Zealand Intensive Care Society (ANZICS)

The Australia New Zealand Intensive Care Society (ANZICS) maintains the Adult Patient Database (APD) which contains information on all patients admitted to Intensive Care Units (ICU) including risk adjustment for mortality. Data for Victorian patients were extracted according to postcodes (ANZICS, 2021).

The ICU codes use the A3 diagnostic code - Acute Physiology and Chronic Health Evaluation (APACHE) II, a disease classification based on severity, which provides a risk classification for severely ill hospitalized patients in a defined group (Knaus, 2002). These are technically Diagnosis

Related Groups (DRG). However, ANZICS does not use ICD-10 coding, hence the codes for patients who had been admitted in ICU had to be linked with their unique identifier from the Emergency Department or other hospital administrative data to match the principal diagnosis.

The advantage of the APACHE II code is that it provides rich data that are not in other hospital administrative databases, e.g. length of stay, biochemistry results, and patient observational data (temperature, usage of ventilators etc.) (Knaus, 2002).

The datasets used in the analysis reported in this thesis are limited to adults only, aged 16 years and older, do not include pediatric cases, during the period from 1st July 2000 to 30th June, 2014, covering 14 years.

4.4.4 Austin Health

The Victorian Spinal Cord Service at Austin Health is one of six specialist services in Australia. It provides services for acute management and rehabilitation for people with traumatic spinal cord injuries from Victoria, Tasmania and the Riverina region of NSW, and is part of Victoria's State Trauma System (VSTSR, 2021).

Austin Health serves as a funnel for patients first admitted to either Alfred Health or Melbourne Health, who require specialist management, as Austin Health is the only Centre in Victoria which provides specialist rehabilitation for patients with traumatic SCI (Austin Health, 2021).

The information received from the Austin Hospital was for patients with spinal injury (SI) rather than spinal cord injury (SCI), so that patients with SCI had to be differentiated from the larger group.

The Austin Hospital provided us with 5 datasets:

i. VAED – contained datasets from 1st July 1998 to 30 June 2015
ii. VAMD - contained datasets from 1st July 1998 to 30 June 2015
iii. ICU contained datasets from 1st July 1998 to 30 June 2015
iv. Emergency Department (ED) discharge summaries, deidentified, with information on cost of medical utilization
v. ED discharge summaries, deidentified, with information on transfers of patients

Austin VAED and VEMD

From the three internal datasets (VEMD, VAED and ICU), a total of 3, 698 patients had a spinal injury during the study period. Of these, 1,078 patients with SCI were identified. During the study period, these patients had 23,401 episodes of readmission to the Emergency Department (ED).

Austin ICU

Of the total number of patients with SCI, 681 were admitted to the Intensive Care Unit (ICU) with a total of 859 episodes.

Patients admitted to ICU did not have ICD codes and post codes, and so this information was extracted through linkage with VAED and VEMD. ICD codes for only 89 patients were extracted from VAED and VAED data. The remainder were coded manually using Diagnosis Related Group (DRG) descriptions.

4.4.5 Alfred Health

The Alfred Hospital provided three datasets:

i. Deidentified datasets from ANZICS - APD, which contained historic data going back to 1994 and submitted to ANZICS
ii. Deidentified data of patients with spinal injuries between 2000 and 2006 inclusive. There was a mixture of spinal injuries and spinal cord injuries.
iii. Deidentified data of patients with spinal injury from July 2006 to December 2015, including basic outcome information, severity of illness and chronic health information.

Alfred: VAED and VEMD

From a total of 2,004 patients with spinal injury from VEMD & VAED datasets, data for 1,298 patients with SCI were extracted together with 5,465 readmission episodes for these patients. Of these, 155 patients were excluded, as their first admission dates were not in the period of study (2000-2014) and subsequent readmissions for these patients were excluded.

Alfred: ICU

From a total of 625 patients with spinal injuries admitted to ICU, 217 patients with SCI were identified. Length of stay (LOS) in ICU was calculated using admission and discharge dates.

Patients admitted to ICU did not have ICD-10-AM codes. ICD codes were extracted from VAED and VEMD data as well as from DRG descriptions (e.g. Cervical injury C1). ICD codes could not be obtained for 101 patients from ICU; however, 91 of them were transferred to the Austin Hospital. These were matched using determinant methods, by concatenating Surname and DOB. ICD codes were obtained from DRG descriptions for the remaining 10 patients.

4.4.6 Royal Melbourne Hospital

The Royal Melbourne Hospital provided us with 4 datasets from 1st July 1998 to 30 June 2015.

i. VAED administrative datasets
ii. VEMD administrative datasets
iii. ICU episodes
iv. Readmissions

RMH VAED and VEMD

From a total of 3,260 patients with spinal injury, 253 patients with SCI were identified from VAED and VEMD datasets between 1st January 2000 to 30th June 2014. There were 4,512 Emergency Department admissions for these patients. Postcodes were not available for 1,186 readmission episodes and were extracted from VAED and ICU datasets to complete the information.

There was a total of 33,162 readmission episodes for all spinal injury patients from the three internal datasets. From these, 4,512 readmissions for SCI were extracted. Each row (episode) had on average of 25 ICD codes. Each individual code was separated (112,800 ICD codes) and these codes were grouped into medical and non-medical block codes. Altogether, 960 rows (episodes) of these codes were re-coded individually, and 1,626 ICD codes were separated and categorized further into group codes (637 blocks).

Royal Melbourne Hospital: ICU

Of the 253 patients with traumatic SCI extracted from VAED and VEMD, 181 were admitted to ICU at the RMH.

From the ICU datasets, it was observed that there were 418 admissions of patients with SCI, and 181 patients had multiple admissions over the period between 2000 and 2014. Seventy-two patients admitted to ICU did not have ICD codes. Of those, 54 were admitted to the Austin Hospital and were clinically matched to extract ICD codes.

4.5 Scope

It is not the intention of this research to link all the identified datasets i.e. from financial custodians, statutory custodians and clinical custodians. Nor does the study involve linking clinical health information such as pharmacy, pathology, radiology and rehabilitation.

4.6 Statistical analysis

Statistical analyses were conducted using Microsoft Excel (2019) for simple tests, and software package Stata 13 (StataCorp LLC, College Station TX, USA, 2014) for complex tests which are described below:

- Descriptive statistics (median, inter quartile range (IQR), mean and standard deviation) were applied to describe the study population.

- The *t*-test and Pearson chi-squared test were applied to compare continuous variables and binary variables, respectively, with the level of significance defined as $p<0.05$. Fishers' exact method was applied (our sample violated assumptions for chi-squared) to test the difference between male and female deaths.

- Logistic regression was applied to investigate the relationship between comorbidities and death, using the extended Elixhauser Comorbidity Index (ECI).

- Multilevel gamma regression was used to investigate the relationship between ECI and overall length of stay in ICU.

4.7 Data coding – ICD-10-AM and DRG

The International Classification of Disease -10th version (ICD-10) was introduced worldwide, beginning in the late 1990s, to classify diseases and other health problems recorded on many types of health records, including death certificates and health records. It is also used worldwide for retrieval of diagnostic information for clinical and epidemiological studies as well as for compilation of national morbidity and mortality statistics by World Health Organization member states (WHO, 2013).

The Australian Modification (ICD-10-AM) was introduced in July 1998 in Victoria, New South Wales, the Australian Capital Territory and the Northern Territory and in the remaining States in July 1999. The Australian modification was necessary to include Australian specific disease as well as to incorporate procedures based on the Commonwealth Medicare Benefits Schedule (MBS) of fees for health services. However, mortality is recorded as ICD-10 as it is reported to WHO which uses ICD-10 (Roberts et al., 1998).

The Australian classification comprises of three classifications as below:

- International Statistical Classification of Diseases and Related Health Problems, Tenth Revision, Australian Modification (ICD-10-AM), which is used to classify diseases and other health problems
- Australian Classification of Health Interventions (ACHI), which is used to classify procedures and interventions
- Australian Coding Standards (ACS), which specifies coding standards that provide guidelines to assist users of the classifications in obtaining consistency in clinical coding nationally (IHPA, 2021).

In Australia, the ICD-10-AM/ACHI/ACS is used for both public and private hospitals to code health data whereas ICD-10 is used for mortality data.

The ICD-10-AM codes uses an alphabet which shows category, dot (.), followed by numbers indicating etiology and location (Figure 4.1).

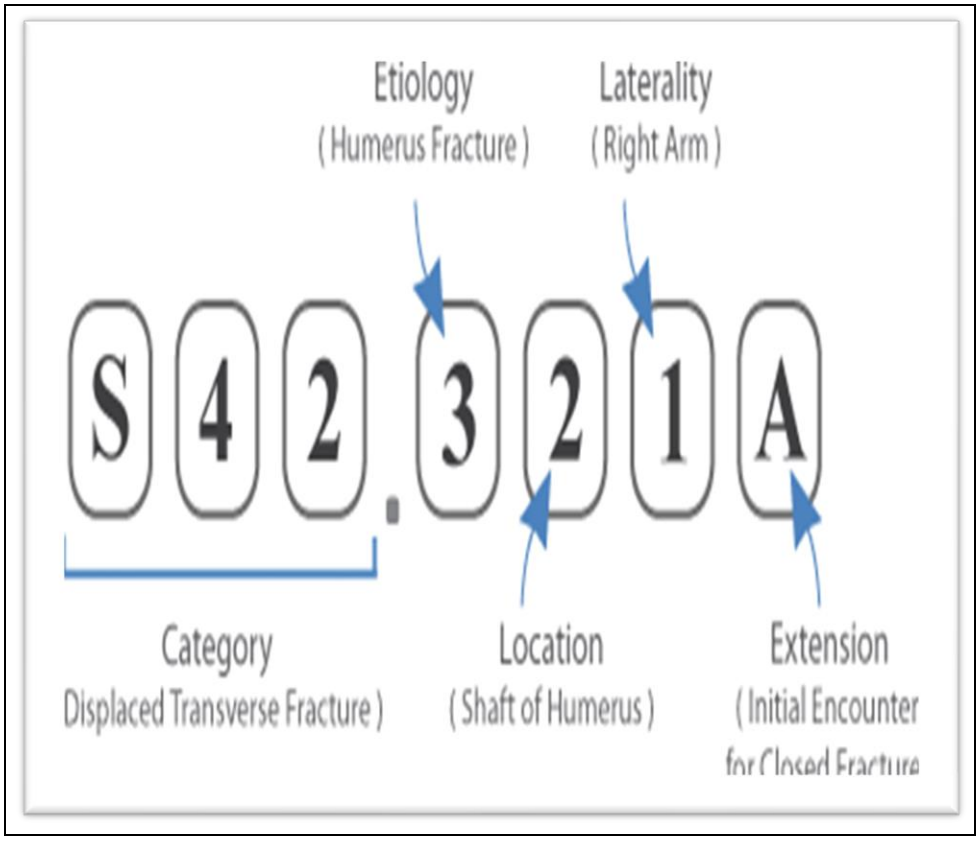


Figure 4-1 Example of ICD-10-coding

(A displaced transverse fracture of the shaft of the humerus, right arm, an initial encounter for closed fracture)
The ICD-10 is much more accurate and specific, and it provides more information compared to the corresponding ICD-9 code. For the example of the case in Figure 4.1, the corresponding ICD-9 of 812.21, only describes a closed fracture of the shaft of the humerus (Nextgen, 2021).

The first digit in an ICD-10 code is always a letter (any letter but "U"). The letter "U" is used for accidents as a result of sports, such as basketball or diving. The second digit is always a number, and the remaining digits can be any combination of numbers and letters. The ICD-10-AM includes disease codes specific to Australia, and ensures a consistent classification of procedures in the public and private sectors, as well as in ambulatory situations, to facilitate implementation of the fee schedule (ACCD, 2018).

A full list of ICD-10-AM codes is included in Appendix 4C.

4.7.1 Intensive Care Unit coding

Patients admitted to ICU do not have standard ICD coding, unlike VEDM or VAED. This is because they are coded by physicians and occasionally by trained ICU nurses. Their inpatient data is kept in a different database, managed by ICU specialists.

Table 4-1 Example of ICU coding

Patient	ICD-10-AM #	Diagnosis 1	Diagnosis C5
Patient C	S14.75	C5/6 spinal cord injury	Complete C5
Patient T	S24.74	T6/T7	T7 Paraplegia

Manual coding from the diagnosis 1 and 2, which was then verified against transfers at the Austin hospital

The ICD-10-AM equivalent for C5/6 is functional SCI S14.75 and for T6/7 it is thoracic SCI S24.74.

A full list of ICD-10 AM codes for Spinal Cord Injury included in the study is provided in Appendix 4D.

4.8 Data normalization

After ethics approval was obtained from the respective hospitals, requests were submitted to the chief data administrators of each hospital for extraction of patient information according to the guidelines.

A determinant clinical data linkage method was used to link three internal datasets from Austin Health. The internal linkage involved linking data from VAED, VEMD and ANZICS-APD.

Data were linked using the hospital UR (Unit Record) number, episode number and hospital admission dates. The dataset was subject to a thorough cleaning process known as ‘normalization’, where data quality such as duplication and data consistencies were checked.

The normalization process was performed in accordance with the ANZICS-APD recommendations (ANZICS, 2021) (Cook et al., 2008; Stowa et al., 2006) and government regulations (Bohensky et al., 2011; Stowa et al., 2006). Once normalized, all three datasets were linked using deterministic data linkage, as all the data had a unique identifier and the exact spelling

of surnames and date of birth for all participants. This method is more robust and stable than probabilistic linkage (Christen, 2012; Karmel et al., 2010). After normalization, data were analyzed according to pathophysiology, demographics, and risk factors. Once linkage was complete, linkage keys were assigned and the identifiers stripped from the analysis data set to ensure confidentiality of data. The de-identified data were entered into a Microsoft Excel spreadsheet and analyzed using a special algorithm from Microsoft Access to avoid duplicate records, and to ensure that data quality was adequate, as the success of a linkage study relies on the quality of the datasets (El-Sofany et al., 2010).

Inconsistencies in data were found during the study as follows:

4.8.1 Inconsistencies in Age

Age was recorded in whole numbers in some cases, or the date of birth. A formula was written to convert date to whole number representation. At the Alfred hospital, two patients were under 16 years. Although age at admission was provided, this was incorrect when checked against date of birth (DOB). These two patients were excluded from further analysis.

4.8.2 Inconsistencies in Sex

A mixture of lower and upper case and full word or first letter was used to record sex, e.g. Female, F, f, Male, M, m. Instances of human error occurred where the same patient was recorded as male or female on four separate occasions, as can be seen in the example below, where the same patient, male, was recorded as female on one occasion - with no evidence of sex change.

Table 4-2 An example of inconsistencies with sex

Age at admission	Date of admission	First Name	Second Name	Sex
45	11-04-13	John	TRAIN	F
45	16-05-13	John	TRAIN	M
45	06-06-13	John	TRAIN	M
45	14-06-13	John	TRAIN	M

This error was found during the validation process, validating against ED discharge summaries. Human error is never totally avoidable; but this example shows the importance of a validation process.

4.8.3 Inconsistencies with principal diagnosis

Inconsistencies existed in internal hospital datasets with respect to the principal diagnosis. This involved the use of multiple codes; e.g. a patient might be coded using one code in one database,

and with another code in another database. This was apparent in diagnoses of thoracic and lumbar level injuries. When there were discrepancies, the ICU description was used as the reference data on which to make a decision about the principal diagnosis.

Inconsistencies were found in the data from all three hospitals:

- Coding issues. Some codes had decimals while others did not, e.g. S14. s14, s1400, s14.00. The prefix was upper case in some instances, but mostly lower case was used.
- Medical reasons for readmission were presented differently in different hospitals. Austin codes were presented in in a form not consistent with the ICD-matrix, e.g., S1476 instead of S14.76. This had to be fixed.

Mismatching between two hospitals. Often when patients were admitted to trauma hospitals such as the Alfred and RMH, they were coded as having an unspecific SCI, as it is not possible to completely diagnose the exact level of the injury at the initial admission because the patient needs to be able to cooperate with the clinical assessment to determine the level of paralysis and sensory loss. For example, a patient admitted to the RMH with a thoracic unspecific SCI (S24.70) was diagnosed as having functional cervical SCI (S14.75) once transferred to the Austin (Table 4.3).

Table 4-3 An example of inconsistencies with principal diagnosis

Region	Hospital	Admission Date	Discharge Date	Principal Diagnosis	ICD-10-AM
Gippsland	RMH	07-Jul-06	07-Jul-06	S24.70	S12.23, S14.10, S24.70,
Gippsland	Austin	7-Jul-06	17-Aug-06	S14.75	B96.5, F10.3, J22, L27.0, N39.0, R11, R73, S12.23, S13.15, S14.12, S14.75, U73.9, V43.69, Y40.8, Y42.3, Y92.22, Y92.40, Z72.0
Gippsland	Austin	17-Aug-06	13-Dec-06	S14.75	F10.3, G82.56, S12.23, S13.15, S14.12, S14.75, U73.9, V43.69, Y92.40, Z50.9, Z72.0

4.8.4 Inconsistencies with ICD-10-AM

Table 4.4 shows a typical example of readmission of a patient. Column A contains the ICD-10-AM codes. The inconsistencies are evident in that some codes have full-stops, whilst others do not have anything after them. The current form was not possible to match with the ICD-10-AM master file to obtain medical description, hence a formula was written to make the codes consistent:

`{=LEFT (A1-3)}, where A is a code column.`

Table 4-4 An example of readmissions

ICD-10-AM	Left & Trim #	Medical description
L89.1	L89	Decubitus ulcer and pressure area
I21	I21	Acute myocardial infarction
N39.0	N39	Other disorders of urinary system
S32.0	S32	Fracture of lumbar spine and pelvis
L89	L89	Decubitus ulcer and pressure area
G47.8	G47	Sleep disorders
J06	J06	Acute URTI multiple & unspecified sites
R45.8	R45	Symptoms signs involving emotional state
K56	K56	Paralytic ileus & intestine without hernia
N30.8	N30	Cystitis
G47.32	G47	Sleep disorders
L03.11	L03	Cellulitis
N20.1	N20	Calculus of kidney and ureter
M84.27	M84	Disorders of continuity of bone
L98.8	L98	Other disorders skin & subcutaneous tis NEC
L89.2	L89	Decubitus ulcer and pressure area
N39	N39	Other disorders of urinary system

[# Trim function takes away spaces left and right]

4.9 Management of data inconsistencies

The time series analyses explored the demographics of patients with SCI, using the following variables: principal diagnosis, age group, sex, region where they were admitted (not where the accident occurred), place of residence, reasons for readmissions, and risk factors.

4.9.1 Age Range

Date of birth (DOB) was used to calculate age at the time of admission. As reported in section 4.6.1 DOB recorded in the datasets was not consistent. Some had precise age in years and months; others had actual date of birth. DOB was also in either American or English format. To make data consistent in this thesis, DOB was converted into age at the time of admission.

Example: Age from DOB

```
{=(N3-E3)/365.25}
```

Where N3= date of admission, E3=DOB

Two-step programs were written to calculate age and classify them into five age range groups: 17-30 years, 31-45 years, 46-60 years, 61-74 years, 75+ years.

Example: Convert ages into five different age ranges:

{=IF(F2>75,"76+", IF(F2>60,"61-75", IF(F2>45,"46-60", IF(F2>30,"31-45", IF(F2>15,"16-30",""))))))}

Where F = age.

4.9.2 Sex

There were inconsistencies with recording of sex in the datasets received as per section 4.6.2. Some data had "female" and "male", others had 'F' for female and 'M' for male. Neither was the capitalization consistent. Data were made consistent as part of data cleansing; all records with female were set as capital F, males set as capital M.

Example:

Alfred Health provided data as "female" and "male"; an Excel formula was written to change female to F, male to M as below:

{=Upper(LEFT(G2,1))}, change to M from male and F from female, then copy and paste (special value) where G=sex.

4.9.3 Analysis of regions

The postcodes provided were those where patients resided rather than where accidents had occurred. These were grouped according to six health network regions identified by the Victorian Department of Health and Human Services: Gippsland, Hume, Barwon South West, Grampians, and Loddon Mallee, as well as Metropolitan region (VMC, 2021). Grouping region data in this way is necessary in order to plan the types of health services available post-trauma.

Because the Metropolitan region is densely populated and had a higher incidence of accidents, postcodes in the Metropolitan region were further divided into Eastern, Southern, Northern, Western and East-Southern regions according to electoral boundaries (VEC, 2021).

To obtain incidence per 100,000 population, Australia Bureau of Statistics (ABS) has been used to as population denominator for each period. ABS defines place of residence as:

> *"that place where each person has lived or intends to live for six months or more from the reference date for data collection"* (ABS 2013).

Once all the post codes were separated into 4-digit numerics, then they were categorized into regions and metropolitan areas.

Postcodes from the Victorian Electoral Commission were used to allocate individual patients living in metropolitan areas. A complete list of all postcodes was put in together to create a master file to allocate each individual patient (Appendix 4A).

Locality step 1 – Separation by States

The datasets had 3,905 rows of postcodes. These were separated according to States. The following formula was written to separate patients by States.

```
{=IFERROR(VLOOKUPIF(LEFT(J2,1)="2","NSW",IF(LEFT(J2,1)=”4”,”Queensland”,
IF(LEFT(J2,1)=”5”,”South Australia”, IF(LEFT(J2,1)=”6”,”Western Australia”,
IF(LEFT(J2,1)="7","Tasmania","Other"))))))}
```

where J represents a column of postcodes.

The above formula will check each patient's post code and categorize into metropolitan areas, as well as into regions within Victoria. For instance, if the patient's postcode starts with '2', that will categorize into NSW, if '3', then Victoria, if '4' then Queensland, if '5', 'South Australia', if '6', Western Australia, if '7', Tasmania.

Locality step 2 – Separation, Victorian Region

The majority of patients resided in Victoria. The postcodes were separated and tabulated according to six network regions in Victoria: Gippsland, Hume, Barwon South West, Grampians, Loddon Mallee, and Metropolitan regions.

A formula was written to categorize all the postcodes into regions:

```
{=VLOOKUP('VAEd'!L463,[PostCode1.xlsx]Total!$A$2:$B$656, 2,FALSE)}
```

An example of separation by Victorian Regions is shown in Table 4.5 and Appendix 4A.

Table 4-5 Separation by Victorian Regions

Locality Name	Post Code	Region Name
Woodend	3442	Grampians
Barrabool	3221	Barwon-South West
Hallora	3818	Gippsland
Eildon	3713	Hume
Bendigo	3523	Loddon-Mallee
Redbank	3477	Grampians
Balwyn North	3104	Eastern Metropolitan

Locality step 3 – Separation by Metropolitan Area

The metropolitan area is densely populated. All postcodes in the metropolitan region were further divided according to electorate, and tabulated according to incidence per 100,000. Table 4.6 illustrates post codes and matching region name.

Table 4-6 Separation by Metropolitan Regions

Post Code	Municipality Name	Region Name
3011	Maribyrnong City Council	Western Metropolitan
3006	Melbourne City Council	Southern Metropolitan
3106	Manningham City Council	Eastern Metropolitan
3046	Moreland City Council	Northern Metropolitan
3171	Greater Dandenong City Council	South-Eastern Metropolitan

If a patient lived in postcode 3011, s/he would be classified as 'Western Metropolitan' region for the analysis. A full list of metropolitan localities by post code is shown in Appendix 4B.

4.9.4 Principal diagnosis

Normally the first code is the principal diagnosis. Principal diagnosis codes are reported by the medical practitioners reflecting the disease, injuries. patient characteristics and circumstances. The maximum number of diagnoses varies from state to state but in Victoria, one to forty principal diagnoses can be reported using the ICD-10-AM/ACS/ACHI (VAED, 2013). However, this was not the case from our records. There were often between 24 and 44 codes, all mixed up and in random order.

The principal diagnosis and secondary diagnosis were separated into different columns. The diagnosis was selected after consultation with clinicians and the Department of Health (See Table 4.7). After consultation with specialists, Department of Health and review of journal papers, 44 principal diagnoses for traumatic SCI were decided, as below in Table 4.7.

There were inconsistencies with the formatting of codes: some had lower/upper case letters, separated by '.'; others were not separated by dots. For data to be consistent, all letters were capitalized and dots were inserted in order to match the ICD-10 format.

The following algorithm was used:

Example: to separate codes to two decimal places. To put dot in ICD codes: i.e. S1201, S12.01 or S1421.2

```
{=IF(MID(H2,4,1)<>".",CONCATENATE(LEFT(H2,3),".",RIGHT(H2,LEN(H2)-3)),H2)}
```

where H represents principal diagnosis column, concatenate means joining two strings together.

Example 2: In the case of Austin Pilot Study, principal diagnosis and description were listed together: (S14.75 Functional spinal cord injury, C5)

To separate ICD codes from description

```
{=RIGHT(AF3,LEN(AF3)-FIND(" ",AF3))}
```

where AF3 is principal diagnosis
Results: To separate S14.75 to one column and description to another column

Example 3: A010 (put dot after A01.0)

```
{=IF(LEN(A4)>3,CONCATENATE(LEFT(A4,3),".",RIGHT(A4,LEN(A4)-3)),A4)}
```

(If length is >3, put dot (.) after 3, where A4 is ICD code)

Table 4-7 **List of principal diagnosis**

ICD	Description
S14.0	Concussion and oedema of cervical spinal cord
S14.1	Other and unspecified injuries of cervical spinal cord
S14.10	Injury of cervical spinal cord, unspecified
S14.11	Complete lesion of cervical spinal cord
S14.12	Central cord syndrome (incomplete cord injury) of cervical spinal cord
S14.13	Other incomplete cord syndrome of cervical spinal cord
S14.2	Injury of nerve root of cervical spine
S14.3	Injury of brachial plexus
S14.70	Functional spinal cord injury, cervical level unspecified
S14.71	Functional spinal cord injury, C1
S14.72	Functional spinal cord injury, C2
S14.73	Functional spinal cord injury, C3
S14.74	Functional spinal cord injury, C4
S14.75	Functional spinal cord injury, C5
S14.76	Functional spinal cord injury, C6
S14.77	Functional spinal cord injury, C7
S14.78	Functional spinal cord injury, C8
S24.0	Concussion and oedema of thoracic spinal cord
S24.10	Injury of thoracic spinal cord unspecified
S24.11	Complete lesion of thoracic spinal cord
S24.12	Incomplete cord syndrome of thoracic spinal cord
S24.70	Functional spinal cord injury, thoracic level unspecified
S24.71	Functional spinal cord injury, T1
S24.72	Functional spinal cord injury, T2/T3
S24.73	Functional spinal cord injury, T4/T5
S24.74	Functional spinal cord injury, T6/T7
S24.75	Functional spinal cord injury, T8/T9
S24.76	Functional spinal cord injury, T10/T11
S24.77	Functional spinal cord injury, T12
S34.0	Concussion and oedema of lumbar spinal cord [conus medullaris]
S34.1	Other injury of lumbar spinal cord [conus medullaris]
S34.2	Injury of nerve root of lumbar and sacral spine
S34.3	Injury of cauda equina
S34.4	Injury of lumbosacral plexus
S34.5	Injury of lumbar, sacral and pelvic sympathetic nerves
S34.6	Injury of peripheral nerve(s) of abdomen, lower back and pelvis
S34.70	Functional spinal cord injury, lumbar level unspecified
S34.71	Functional spinal cord injury, L1
S34.72	Functional spinal cord injury, L2
S34.73	Functional spinal cord injury, L3
S34.74	Functional spinal cord injury, L4
S34.75	Functional spinal cord injury, L5
S34.76	Functional spinal cord injury, sacrum
T09.3	Injury of spinal cord, level unspecified

4.9.5 Length of Stay (LOS)

Length of ICU stay was calculated from care unit admission and discharge date and matched against principal diagnosis and total weighted equivalent inlier system (WEIS) for the Austin Hospital.

Length of stay was calculated in days from admission and discharge dates: e.g. ICU admission date: 7/1/2000, ICU discharge date: 10/1/2000: LOS = 3 days.

The length of stay for all 44 individual principal diagnoses was calculated and separated into three main groups; Cervical, Thoracic and Lumbar SCI. The percentage of readmissions for each group was calculated and the interquartile range, which shows the middle dispersion of a dataset, was calculated.

4.10 **Readmissions**

A prospectively maintained database of all patients who were admitted to Alfred, Austin and Royal Melbourne Hospitals between 2000 and 2014 inclusive, was merged with data from VEMD, VAED and ICU hospital registries, to identify readmissions. These included all readmissions after discharge from the initial traumatic injury, based on discharge dates.

Each patient had up to 44 ICD-10 codes covering principal diagnosis, comorbidities, risk factors, place and type of injury, family history, medications, and personal and support details. All readmissions were coded with T91.3 (Sequelae). All ICD-10 codes used were separated into medical and non-medical ICD-10 codes using the following formula:

```
{=IF(ISERROR(LEFT(N2,FIND(",",N2)-1)),N2,LEFT(N2,FIND(",",N2)-1))}
```

where N is a column with principal diagnosis.

There were over million ICD codes for the cohort and these had to be grouped and then matched to description before the analysis. A macro was written to undertake this process as below:

4.10.1 Macros for readmissions

```
Sub ValidateCodes()//To validate code//
    Dim Codes() As String
    Dim Text As String
    Dim Count As Long

    Application.Goto ActiveWorkbook.Sheets("Sheet2").Cells(2, 3)
    LastCode = Cells(Rows.Count, 1).End(xlUp).Row
    Application.Goto ActiveWorkbook.Sheets("Sheet1").Cells(2, 16)
    LastRow = Cells(Rows.Count, 1).End(xlUp).Row
    For x = 2 To LastRow
        Text = ActiveSheet.Cells(x, 16).Value
        Codes = Split(ActiveSheet.Cells(x, 16), ",")
        For Z = 0 To UBound(Codes) - 1
            With Worksheets(2).Range("a1:" & LastCode)
                Set Found = .find(Codes(Z), LookIn:=xlValues)
                If Found Is Nothing Then
                    If ActiveSheet.Cells(x, 17).Value > "" Then
                        ActiveSheet.Cells(x, 17) = ActiveSheet.Cells(x, 17) & " " &
Codes(Z)
                    Else
                        ActiveSheet.Cells(x, 17) = Codes(Z)
                    End If
                    Count = Count + 1
                End If
            End With
        Next Z
    Next x
    ActiveSheet.Cells(x + 2, 16) = "Count of invalid codes"
    ActiveSheet.Cells(x + 2, 17) = Count
End Sub

Sub CountCodes()//Count number of codes to verify that we have them all//
    Dim Count As Long
    Dim find As String

    Application.Goto ActiveWorkbook.Sheets("Sheet2").Cells(2, 3)
    LastCode = Cells(Rows.Count, 1).End(xlUp).Row
    For Z = 2 To LastCode
        find = ActiveSheet.Cells(Z, 1).Value & ","
        Count = 0
        y = 16
        x = 2
        Application.Goto ActiveWorkbook.Sheets("Sheet1").Cells(x, y)
        LastRow = Cells(Rows.Count, 1).End(xlUp).Row
        For x = 2 To LastRow
            Length = Len(ActiveSheet.Cells(x, y).Value)
            subtracted = Replace(ActiveSheet.Cells(x, y), find, "")
            missing = Len(subtracted)
            Count = Count + (Length - missing) / Len(find)
        Next x
        Application.Goto ActiveWorkbook.Sheets("Sheet2").Cells(Z, 3)
        ActiveSheet.Cells(Z, 3) = Count
    Next Z
End Sub

Sub SplitData()//To separate all codes that were in one row//
    y = 16
    x = 2
    Application.Goto ActiveWorkbook.Sheets("Sheet1").Cells(x, y)
    LastRow = Cells(Rows.Count, 1).End(xlUp).Row
    For x = 2 To LastRow
        Codes = Split(ActiveSheet.Cells(x, 16), ",")
        For Z = 0 To UBound(Codes) - 1
```

```
            ActiveSheet.Cells(x, y + Z + 2) = Codes(Z)
        Next Z
    Next x
End Sub

Sub UniqueCodes()//To determine unique codes used//
    y = 16
    x = 2
    SevenX = 1
    Application.Goto ActiveWorkbook.Sheets("Sheet1").Cells(x, y)
    LastRow = Cells(Rows.Count, 1).End(xlUp).Row
    For x = 2 To LastRow
        Application.Goto ActiveWorkbook.Sheets("Sheet1").Cells(x, y)
        Codes = Split(ActiveSheet.Cells(x, 16), ",")
        Application.Goto ActiveWorkbook.Sheets("Sheet7").Cells(SevenX, 1)
        For Z = 0 To UBound(Codes) - 1
            ActiveSheet.Cells(SevenX, 1) = Codes(Z)
            SevenX = SevenX + 1
        Next Z
    Next x
End Sub

Sub Summarise()//Count into block no and make block no Bold//
    y = 1
    x = 2
    Application.Goto ActiveWorkbook.Sheets("SummariseByCode").Cells(x, y)
    LastRow = Cells(Rows.Count, 1).End(xlUp).Row
    For x = 2 To LastRow
        If InStr(0, ActiveSheet.Cells(x, y).Value, ".") = 0 Then
            If ActiveSheet.Cells(x, 2).Value > 0 Then
                ActiveSheet.Cells(x, 2).Interior.ColorIndex = 5
            End If
            ActiveSheet.Cells(x, 2).Font.Bold
            ActiveSheet.Cells(x, 2).Value = ActiveSheet.Cells(x, 2).Value + Count
            Count = 0
        Else
            Count = Count + ActiveSheet.Cells(x, 2).Value
        End If
    Next x
End Sub
```

From a total 8,459 readmissions (episodes), 78,205 individual ICD-10-AM codes were extracted and these codes were separated into medical (13.8%, n=10,812) and non-medical (86.2%, n=67,393) codes as shown in Table 4.8.

Table 4-8 Extraction of ICD-10-Block codes

Description	ICD-10-AM codes
Cancer	C0-C6, C40-C43, C45-C49, C70-C76, C80-C85, C883, C887, C889, C900, C901, C91-C93, C940, C941, C942, C943, C95, C9451, C96, C947
Chronic pulmonary disease	J40-J46; J60-J67
Chronic renal disease	N01, N03, N18, N19, N25, N052, N053, N054, N055, N056, N056, N072, N073, N074
Congestive heart failure	I50
Connective tissue disease	M050-M053, M058-M060, M063, M069, M32, M332, M34, M353
Cerebrovascular Accident	G450- G452, G454, G458, G459, G46, I60, I62-I66, I670-I672, I674-I679, I69, I681, I682, I688
Dementia	F00, F01, F02, F03, F051
Diabetes, complicated	E102-104, E112-E114, E132-E134, E142-E144
Diabetes, uncomplicated	E101, E105, E109, E111, E115, E119, E131, E139, E141, E149
Hemiplegia	G81, G041, G820, G821, G822
HIV	B20, B21, B22, B23, B24
Liver disease (mild to moderate)	K73, K702, K703, K717, K742-K746
Metastatic cancer	C77, C78, C79, C80
Moderate to severe liver disease4.5	K721, K729, K766, K767
Myocardial Infarct	I21, I22, I252
Peripheral vascular disease	I71, R02, I790, I739, Z958, Z959
Ulcer disease	K25, K26, K27, K28
Sports related injuries: (281 codes: U50.0-U73.9)	Football (U50.0), Cricket (U51.1), Martial arts (Tae Kwon Do U61.36), horse racing (U61.36)
Causes of injuries: (2,811 codes: V00.0)	Roller skates (W02.0), ice skates (W02.5), snow board (W02.4), (W02.8), scooters (W02.6), bitten by dog (W54.0), drowning (W67.0), Assaults (Y08.0), falls from high place (Y30.0)
Causes of injuries: (384 codes: Y40-Y91.9)	Failure of sterile precautions during surgical and medical care (Y62), Sequelae with surgical and medical care as external cause (Y88), Evidence of alcohol involvement determined by blood alcohol level(Y90)
Place of incidents: (71 codes: Y92.x)	home (Y92.0), kitchen (Y92.04), prison (Y92.10), school (Y92.21), sports and athletics (Y92.3), streets and highway (Y92.4), industry and construction (Y92.6), farm (Y92.7)

4.10.2 Reasons for readmission

Medical codes were further grouped according to specific conditions pertinent to SCI. The secondary conditions and corresponding ICD-10-AM codes specific for SCI are included in Table 4.9 below.

Unlike in principal diagnosis, where block codes were used to group patients into four main groups: cervical, thoracic, lumbar and sacral, caution was required so as not to group the secondary conditions according to block codes, as this could dilute the data and misrepresent the actual conditions. For example, N39.0 is urinary tract infection, but N39.1 is persistent proteinuria. Even though both belong in the category of diseases of the urinary tract, the cause of first is infection, and the latter may be the result of a kidney disorder. Complication codes and corresponding ICD-10-AM codes for SCI specific conditions are shown in Table 4.9.

Table 4-9 SCI-related secondary conditions and corresponding ICD-10-AM codes

Complication		ICD-10-AM codes
Urinary	Urinary tract infection (UTI)	N39.0
	Urinary incontinence and polyuria	N39.3, N39.4, R30.0, R31, R32, R35, R39.8
	Urinary retention	R33
	Prostatitis	N41.0-N41.9, N42.0-N42.9
	Neurogenic bladder	N31.0-N31.9, G93.4, G95.8
	Urinary calculi	N20.0-N20.9, N21.0-N21.9, N42.0
	Uropathy including hydronephrosis	N13.0-N13.9
	Urethritis	N34.0-N34.3
	Cystitis	N30.0-N30.9
	Bladder cancer	C67.0-C67.9
	Renal cancer	C64, C65
	Urethral stricture	N36.0-N36.9, N37.0-N37.9
	Other urethral complication	N35.0-N35.9
Bowel	Functional intestinal disorders	K59.0-K59.9
	Fissures of the anal and rectal regions	K60.0-K60.5
	Abscesses of the anal and rectal region	K61.0-K61.4
Respiratory	Pneumonia	J13, J15.0-J15.9, J18.0-J18.2, J18.8-J18.9, J20.0, J20.2, J20.8-J20.9
	Pneumonitis	J69.0
	Respiratory failure and pulmonary collapse	J96.0, J96.00-J96.01, J96.90, J96.91, J80, J81, J90, J93, J98.1, J98.6
Other	Fever of unspecified origin	R50.9
	Heterotopic ossification	M61.2, M61.9
	Venous thrombosis	I80.0- I80.9
	Pulmonary embolus	I26, I26.0, I26.9
	Pressure area or ulcer	L89, L89.0-L89.9, L02.3-L02.4, L97
	Sleep apnoea and other disorders	G47.3, G47.30, G47.31, G47.32, G47.33, G47.39
	Orthostatic hypotension	G90.3
	Autonomic dysreflexia	G90.4
	Cellulitis	L03.1, L03.10, L03.11, L03.9
	Chronic pain	R52.1, R52.2, R52.9
	Upper or lower limb fracture	S42, S52, S62, S72, S82, S92, S3201-S32.5, S32.7, S32.8

4.10.3 Total numbers of readmissions

Total admission numbers per patient were calculated. To work out the percentage of readmissions for each patient from total readmissions, the following formula was used to extract the information:

```
{=IF(C2<>C1, VLOOKUP(C2, $AC$2:$AD$1024,2,FALSE),"")}
```

Where C1 & C2 are unique identifiers. If C1 & C2 are the same, look up the table and add admissions. If they are not same, put "0".

4.10.4 Percentage Readmissions

Calculation of percentage of readmissions for the cohort involved data linkage of several files, as not all the files had the relevant information. Readmission files contained patient number and medical codes only. Each patient number was linked using a unique key (surname and date of birth) to match these files.

We needed records of admission and discharge dates of all the readmissions as well as the main causes of medical conditions.

The Austin database had admission dates only. Discharge dates were obtained from emergency discharge summary notes. Causes of medical conditions were obtained from VAED databases. The unique identifier (key) formula was written to extract and match the information:

```
{=concate(C2,C7)}
```

where C2 is the surname and C7 is the date of birth.

The Alfred database had admission and discharge dates but did not have date of birth (DOB), so DOB was obtained from raw data entry combined from 4 separate databases (ICU pre- and post-2005; VAED pre- and post- 2005).

The RMH database contained a unique identifier with admission codes only. This file was missing DOB and other patient details. The unique identifier (key) was used to extract information from 6 databases.

To merge data from all three hospitals in date order, the unique key using the name and date of birth was written to merge all readmissions. There were some patients without DOB but had the

age at admission, which was converted into year of birth then matched with name to create unique keys for them.

4.11 **Comorbidities**

Comorbidities are conditions separate from a principal diagnosis. Comorbidities can be pre-existing, may occur as a consequence of a primary condition, or may be independent of it.

The Charlson Comorbidity Index (CCI) and the Elixhauser Comorbidity Index (ECI) are widely used to classify comorbidities based on the ICD codes found in health administrative data (Thompson et al., 2015). The Charlson Comorbidity Index is fairly simple; it uses 17 indicators and originated from clinical trials for breast cancer (Charlson et al., 1994) whereas the Elixhauser Comorbidity Index is much more sophisticated, based on hospital inpatients, and uses 30 indicators (Elixhauser et al., 1998). As our study cohorts are hospital-based inpatients, the Elixhauser Comorbidity Index is more suitable than the Charlson Comorbidity Index for this study. Moreover, the study included ten more indicators that are specific for SCI but are not included in the ECI. (See Appendix 4E for Charlson Comorbidity Index and Appendix 4F for Elixhauser Comorbidity index). Table 4.10 shows the extended Elixhauser Comorbidity Index of a typical SCI patient where:

- 1-30 Elixhauser comorbidity index
- 31-40 SCI specific comorbidities

The individual ICD-10-AM codes for each patient were compared with the lists in the following tables and checked against existing comorbidities. Patients were assigned ‘0’ if they did not have the condition and ‘1’ if they did. If the patient X had more than one condition in the group, then they would be assigned ‘1’ on another loop through the index. The total comorbidities would then be calculated (Table 4.10).

Table 4-10 Extended Elixhauser index of a typical SCI patient

No	Comorbidity	Patient X	ICD-10-AM codes
1	Congestive heart failure	0	I19.9, III.0., II3.0., II3.2., I25.5., I42.0., I42.5-I42.9, I43., I50.
2	Cardiac arrhythmias	0	I44.1-I44.3, I45.6, I45.9, I47-I49, R00.0, R00.1, R00.8, T82.1, Z45.0, Z95.0
3	Valvular disease	0	A52.0, I05 - I09.1, I09.8, I34 - I39., Q23.0 - Q23.3, Z95.2, Z95.4
4	Pulmonary circulation Disorders	0	I26., I27., I28.0., I28.8., I28.9
5	Peripheral vascular disorders	0	I70., I71., I73.1, I73.8, I73.9, I77.1, I79.0, I79.2, K55.1, K55.8, K55.9, Z95.8, Z95.9
6	Hypertension	1	I10., I11., I12, I13., I15.
7	Paralysis	0	G04.1, G11.4, G80.1, G81., G82., G83.0, G83.1, G83.2, G83.3, G83.4, G83.9
8	Other neurological conditions	1	G10.- G13., G20., G21., G25.4, G25.5, G31.2, G31.8, G31.9, G32., G35.-G37., G40., G41., G93.1, G93.4, R47.0, R56.
9	Chronic pulmonary disease	1	I27.8, I27.9, J40., J41.- J47., J60-J68.4., J70.1, J70.3
10	Diabetes Mellitus [DM]	0	E10.0, E10.1, E10.9, E11.0, E11.1, E11.9, E12.0, E12.1, E12.9, E10.0, E13.1, E13.9, E14.0, E14.1, E14.9
11	Diabetes Mellitus Complicated [DMc]	0	E10.2-E10.8, E11.2-E11.8, E12.2-E12.8, E13.2-E13.8, E14.2-E14.8
12	Hypothyroidism	0	E00., E00.1, E00.2, E00.3, E89.0
13	Renal failure [RF]	0	I12.0, I13.1, N18., N19., N25., Z49.0-Z49.2, Z99.2
14	Liver disease [LD]	0	B18., I85., I86.4, I98.2, K70., K71.1 K71.3- K71.5, K71.7. K72-K74., K76.0, K76.2- K76.9. Z94.4
15	Peptic ulcer disease	0	K25.7, K25.9, K26.7, K26.9, K27.7, K27.9, K28.7, K28.9
16	HIV or AIDS	0	B20., B21., B22., B23., B24.
17	Lymphoma	0	C81., C82., C83., C84., C85., C88., C90.0, C90.2, C96.
18	Metastatic cancer	0	C77., C78., C79., C80.
19	Solid tumour without metastasis	0	C00.-C41., C43- C76., C97.
20	Rheumatic or con tissue disease	0	L94.0- L94.3, M05., M06., M08., M12.0, M12.3, M30., M31.0, M31.2, M31.3, M32-M35., M45., M46.1, M46.8, M46.9
21	Coagulopathy	0	D65.-D69.1, D69.3-D69.6
22	Obesity	1	E66.
23	Weight loss	0	E40.-E46., R63.4., R64.
24	Fluid and electrolyte disorders	0	E22.2, E86., E87.
25	Blood loss anaemia	0	D50.0
26	Deficiency anaemia	0	D50.8., D50.9., D51., D52., D53.
27	Alcohol abuse	1	F10., E52., G62.1, I42.6, K29.2, K70.0, K70.3, K70.9, T51., Z50.2, Z71.4, Z72.1
28	Drug abuse	1	F11.- F16., F18., F19., Z71.5., Z72.2
29	Psychoses	0	F20., F22.-F25., F28.-F30.2, F31.2, F31.5

30	Depression	1	F20.4., F31.3., F31.4., F32.-F34.1., F41.2., F43.2
31	Delirium	0	F05.9,
32	Personality disorder	0	F60.3, F60.6- F60.8, F63., F64., F93., F95., F98.
33	Autonomic dysreflexia [AD]	1	G90.4
34	Bowel complications [BC]	1	K59., K60.0, K60.1, K60.2, K60.3, K60.4, K60.5. K61.0, K61.1, K61.2, K61.3, K61.4
35	Cellulitis	1	L03.1, L03.9, L03.10, L03.11
36	Dementia or Alzheimer's	0	F00., F01., F02., F05.1
37	Hypotension	1	I95.0, I95.1, I95.8, I95.9, G90.3
38	Pressure ulcers	1	L89., L02.3, L02.4., L97.
39	Sleep apnoea	1	G47.3, G47.30, G47.31, G47.32, G47.33, G47.39
40	Urinary complications [UC]	1	N13., N14., N20., N21., N30.-N42., R31- R36., R39.
Total	Comorbidities	14	

Table 4.11 shows snapshot of how Elixhauser comorbidities index is applied: '0' indicates no comorbidities and '1' indicates presence of comorbidities (only 4 comorbidities shown). The total 40 comorbidities are shown Appendix 4 G. This was done for all ICD-10-AM codes listed at each readmission.

Table 4-11 Snapshot of Elixhauser comorbidities for a sample of patients

Sex	Age (years)	Principal Diagnosis	LOS (days)	LOS - ICU (days)	Death	Total no. of comorbidities	1. Congestive heart failure	2. Cardiac arrhythmias	3. Valvular disease	4. Pulmonary circulation Disorders
							01	02	03	04
M	20	S14.75	0.0	0	0	1	0	0	0	0
M	68	S14.73	9.0	9	0	4	0	0	0	0
M	56	S14.75	0.0	0	0	4	0	0	0	0
M	54	S14.74	23.0	0	0	9	0	0	0	0
M	48	S24.75	13.1	0	0	7	0	0	0	0
M	38	S34.1	0.0	0	0	2	0	0	0	0
M	54	S24.12	1.0	0	0	2	0	0	0	1
M	52	S14.71	0.0	0	0	0	0	0	0	0
M	62	S24.77	14.0	0	0	5	0	0	0	0
M	61	S34.1	0.0	0	0	0	0	0	0	0
F	65	S24.77	0.0	0	0	0	0	0	0	0
M	82	S14.75	3.9	0	0	0	0	0	0	0
M	38	S24.75	0.0	0	0	2	0	0	0	1
M	52	S14.1	17.0	17	0	0	0	0	0	0
M	82	S14.12	0.0	0	0	1	0	1	0	0
M	75	S34.1	0.0	0	0	0	0	0	0	0
M	53	S14.75	5.0	5	0	0	0	0	0	0
M	58	S14.73	2.0	2	0	0	0	0	0	0
M	38	S14.75	8.3	0	0	6	0	0	0	0
M	46	S14.73	8.0	8	0	0	0	0	0	0
M	83	S34.1	0.0	0	0	12	2	4	0	0

Once the extended Elixhauser Comorbidities Index for each patient was calculated, the statistical analysis was performed using multivariate regression.

4.11.1 Interval between each readmission

The interval between each readmission was studied. From the time of discharge, ICD-10 codes indicating reasons of readmission were selected for each individual patient. All the ICD-10 data for the interval period of 1, 3, and 6 months and 1–2-years after discharge from the first admission were collected. The individual codes from the ICD-10-AM codes were summarised.

Steps involved in isolating the ICD-10 codes for the analysis were:

1. From the interval, select all intervals up to 30 days – save into another file
2. Select the column with Emergency admissions
3. Separate (delimit) all codes individually to separate codes (excel, data text from, select comma)
4. Make all the codes consistent: no space at the front, all characters to be consistent, dot after one character and 2 numbers so they can be matched from the master file. (Examples of inconsistencies are: L89.9, N39, n77, I10.)
    a. Remove space in front: [=Trim(range)]
    b. Remove first code from the rest of the codes: [=left (range, 4)]
    c. Separate each code separately: use data range, text to column, delimited, select comma.
5. Once all codes are separated and consistent, sum up total number of codes:
    a. Add each column to the first column
    b. Remove blank rows
    c. Copy first column to another column
    d. Use countif function to calculate total ICD-10 codes [=countif(range), column]

An example of a patient readmission is listed as an ICD-10-AM code as below:

{John Smith, 12346: L89.1, I21, N39.0, M48, E16.2, S32.0, L90, G47.8, J06, R45.8, K56}

These ICD-10-AM codes were separated into a column, then “Trim” & “Left” formula was used to make them consistent, then these codes were checked against medical descriptions as below:

The intervals (time difference from the first admission to the next admission) for those patients who had been readmitted were calculated using the formula:

```
{=IF (C2=C1, M2-M1,0)}
```

If the second row is same date as the first row, then calculate difference in date from second to first. If they are not the same patient, then put 0. (first admission only).

A few patients have had multiple readmissions often interchanging between hospitals. When the patient was in ICU, they had different admission and discharge dates each time they had a procedure. One patient could end up having up to 5 readmissions within 2 days. Care had to be taken to make sure that patient readmissions were not doubled up.

As one example of mismatch Table 4.12, a patient was transferred from RMH to the Austin Hospital on 22nd December, 2008. The patient's principal diagnosis was coded as S14.70, but at the Austin, on discharge, the patient was coded as S14.74.

Table 4-12 An example of mismatched diagnosis

RMH: 22-Dec, 2008: **S14.10**, S14.70, S12.1,
Austin: 22-Dec, 2008: D64.9, H54.4, I95.9, S01.0, S01.81, S01.88, S02.1, S02.2, S02.4, S12.1,S12.23,S12.24,S14.0,S14.11,**S14.74**,S51.0,S60.81,S82.82,S93.0,S93.48,U73.9,V03.1,Y92.40

Note that the patient was initially admitted to RMH as a trauma patient where the full diagnosis was not possible and hence the principal diagnosis is recorded as being cervical functional injury unspecified (S14.70). On the same date, the patient was transferred to Austin. On the discharge record, the patient was noted to have functional cervical injury C4 (S14.74), as indicated in bold.

4.12 Risk factors

Risk factors such as alcohol, illicit drugs and tobacco that could have contributed to the accident and could lead to a detrimental effect on overall health of patients were examined. All the ICD-10-AM codes pertaining risk factors were extracted from the original sources (VAED & VEMD) and categorized into block codes below:

- tobacco (Z72.0),
- alcohol (F10.x) & (Z72.2) and
- drug: mental and behavioral disturbance due to opioid (F11.x), cannabis (F13.x), other stimulant (F15.x) multiple stimulants (F19.x), drug use (Z72.2)

Once collated their association with age range and gender was analysed for both living patients as well as for the deaths.

4.13 Deaths

The number of deaths within the cohort were studied and the relationship with the principal diagnosis, sex, age range and comorbidities were analysed.

4.14 Summary

This chapter has provided an overview of methods used for the time series analysis in Chapter 5 (Austin pilot study) and Chapter 6 (Cohort of three hospitals). The chapter has provided the background of the three hospitals, how data were collected and linked, a detailed method for data normalisation, empirical evidence of data inconsistencies, and an explanation of how data inconsistencies were overcome.

The detailed analysis of region explains how the postcodes can be broken into Victoria metropolitan areas and regions where health network is provided. The study provides stratification of patient journey with actual formulas to analyse the admissions, actual number and total percentage of readmissions per patient, main reasons for readmissions, risk factors, comorbidities, intervals, places and causes of injury over a patient's journey.

The actual macros for calculating more than a thousand codes of readmissions for comorbidities (Elixhauser comorbidity), actual formulas for each step and statistics required for the correlations are provided.

Chapter 5

Time Series Analysis (I): Austin Pilot Study

5 TIME SERIES ANALYSIS (I) – AUSTIN PILOT STUDY

5.1 Introduction

This Chapter reports the findings of the retrospective time series analysis of linked datasets for patients with spinal cord injury within Austin Health, collected over a 10-year period. The data have been collected from patients who came through Victorian Emergency Departments (VEMD), intensive care units (ICU) and Spinal Unit (SU) with traumatic spinal cord injuries.

This pilot study was conducted to ensure that all relevant data could be linked in a timely manner prior to undertaking a larger data linkage study involving three separate centres. Data linkage can take a long time, given that the study involved ethics clearance from relevant data custodians as well as the University. Obtaining the correct data from the appropriate people can be challenging as well.

The study aimed to create a profile of patients with SCI, such as age, sex, main causes of injury, places of residence, and reasons for and number of readmissions, and cost of hospitalisation, that can be used to help patients, clinicians, families and health policy makers.

5.2 Setting and Scope

The Victorian Spinal Cord Service at Austin Health is one of six specialist services in Australia. It provides services for acute management and rehabilitation for people with traumatic spinal cord injuries from Victoria, Tasmania and the Riverina region of NSW. It is part of Victoria's State Trauma System (Austin, 2021) and it provides definitive services to all patients with spinal cord injury due to major trauma in Victoria (VSTR, 2021).

Austin Health serves as a funnel for patients first admitted to one of two adult Trauma Centres, Alfred Health or Melbourne Health, who require specialist management, as Austin Health is the only Centre in Victoria which provides specialist rehabilitation for patients with traumatic SCI (Austin, 2021).

5.3 Case selection

The detailed background and methodology, including data normalization, data selection and data coding, has been described in Chapter 4. The relevant details for this study are:

- Datasets: Three internal datasets (VEMD, VAED and ICU) from Austin Health
- Data Period: 1st of July, 1998 to 30th of June, 2008

- Age: 16 years and above
- Data coding: ICD-10-AM

The inclusion criteria for traumatic spinal cord injury are shown in Table 4.7 and were determined following consultation with the Victorian Department of Health and Human Services and consultant physicians from Austin Health. For the purpose of this study, the codes selected were those specifically indicating neurological injury, rather than an injury to the vertebral column alone such as fracture or dislocation as shown in Table 4.7 in the previous chapter. However, the pilot study included two additional conditions that are not specifically included with the principal diagnosis of traumatic spinal cord injury: neuromuscular dysfunction (N31.9) and Sequelae (T91.9). These can include conditions such as bladder dysfunction, pressure ulcer, urinary tract infection which are very common following spinal cord injury. Patients with injury to the spinal cord itself are likely to have a longer ICU stay, as such injuries often lead to higher comorbidities, leading to higher need for medical intervention.

5.4 Statistical analysis

Statistical analysis was done using both Microsoft Excel version 2019 and statistical software package Stata 13 (StataCorp LLC, College Station TX, USA, 2014).

- The *t*-test and Pearson chi-square test were applied to compare continuous variables and binary variables, respectively, with the level of significance defined as $p<0.05$.
- Median (IQR), mean (SD), and percentages were used to describe Weighted Equivalent Inlier Separation (WEIS)
- All graphs were drawn using Microsoft Excel version 2019.
- All validation was performed using Microsoft Access version 2019.

5.5 Results

Over the 10-year period, records of 1,072 patients with SCI from the Emergency Department at Austin Health were examined. Among these, 51 patients had been transferred from Royal Melbourne Hospital (RMH) and 8 patients from Alfred Health. There were 59 deaths over the study period. Data extracted included sex, age group, region of residence, principal diagnosis, and risk factors, as well as major causes of readmissions, which are shown below.

5.5.1 Separation by Sex and Age Range

There were 193 (18.0%) females and 879 males (82.0%) in the Austin pilot study, a female to male ratio of 1:4.6 (Table 5.1).

Table 5-1 Separation by Sex and Age Range

Age Range	Male	Male (%)	Female	Female (%)	Total
16-30	250	28.4%	38	19.7%	288
31-45	232	26.4%	47	24.4%	279
46-60	220	25.0%	45	23.3%	265
61-75	127	14.4%	45	23.3%	172
76+	50	5.7%	18	9.3%	68
Total	879	100.0%	193	100.0%	1072

There was a significant association between gender and age group ($r=0.73$; $p=0.003$), showing that female participants were more likely to be older than male participants.

The proportion of SCI in both males and females is shown in Table 5.1. The highest proportion was noted in the 16-30 years age group (28.4%), with decreasing cases with increasing age. However, in females the highest incidence of SCI was in the 31-45 years age group, followed by similar incidences in the 46-60 years and 61-75 years age groups. The lowest numbers of both males and females with SCI were in the 76+ age group.

Trends in male and female admissions over the period of 10 years are shown in Figure 5.1.

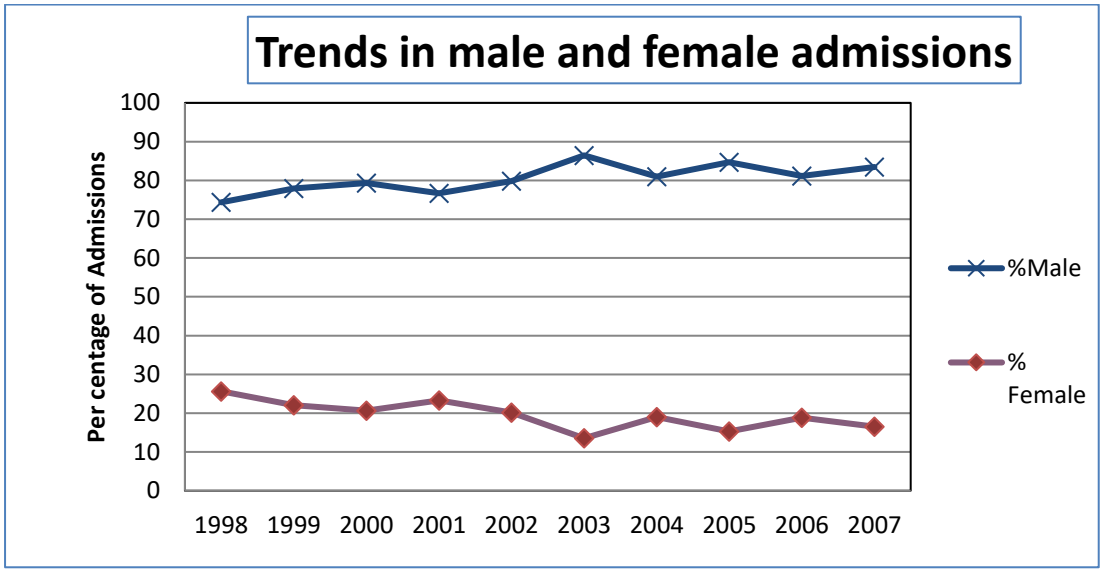


Figure 5-1 Austin Pilot Study: Trends in male and female admissions over 10 years

[Note: year is based on financial year] see Appendix 5A for the raw data & 5B for total admissions

Over the 10-year period, male admissions rose from 74% in 1998 to 83% in 2007, peaking at 86% in 2003. During the same period there was a decline in female admissions from 17% in 1998 to 26% in 2007. There was an 84% increase in male admissions between 2001 and 2002 because of the introduction of the trauma centre.

5.5.2 Separation by principal diagnosis

The major levels of traumatic SCI were extracted and separated according to the ICD10-AM.

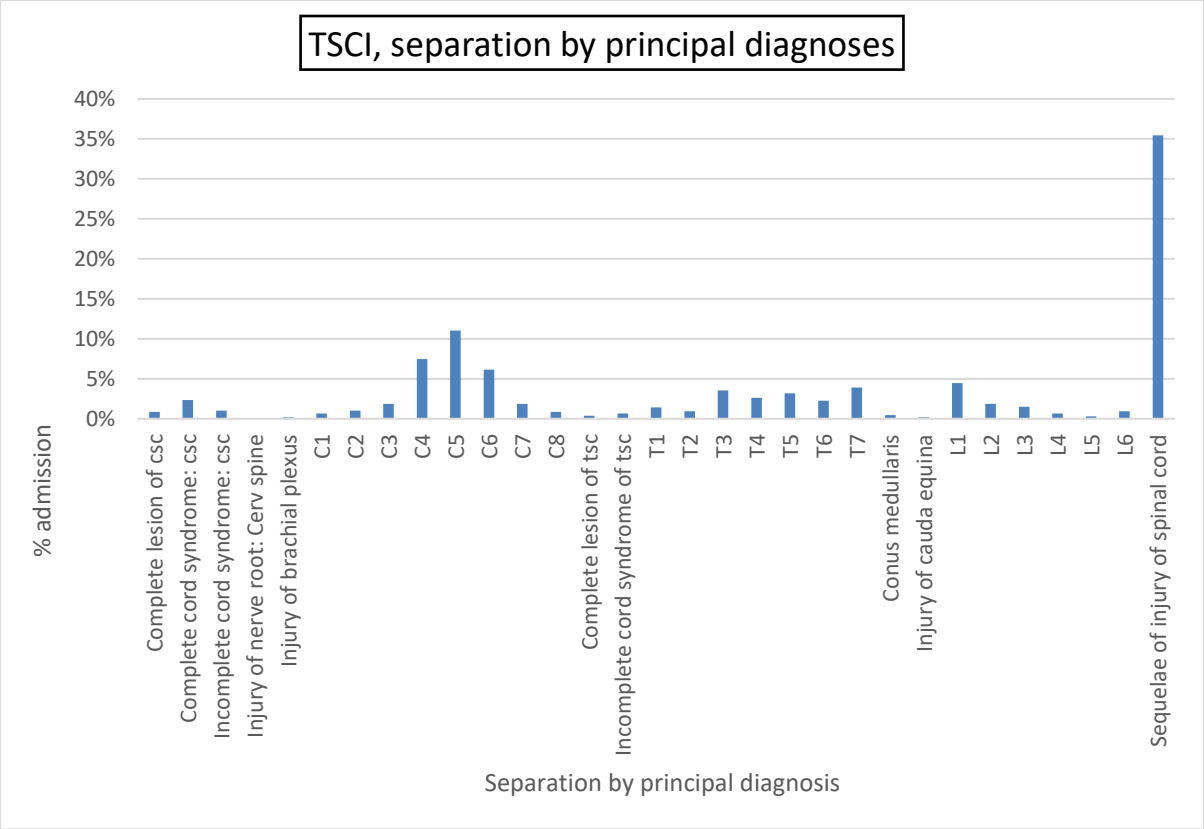


Figure 5-2 Principal diagnoses of patients with traumatic SCI (TSCI) discharged from the Emergency Department 1998-2008.

csc: cervical spinal cord; tsc: thoracic spinal cord, See Appendix 5C for the raw data.

From the overall patient discharge summary, the major reasons for readmission over the whole period were sequelae of SCI (35 %), as expected. The most common level of injury was at the C5 level (11%) followed by C4 (7%), C6 (6%), and those with T3 and L1 equally 4%. These data are not mutually exclusive, i.e. patient can have a complete lesion of the cervical spinal cord (csc) and a lesion at C4.

5.5.3 Re-admissions

ICD-10-AM Codes were categorized and separated into medical and non-medical codes. Medical codes accounted for 23.7% (n=11,361) of the total and included spine-related conditions as well as generic medical conditions, medications, types of procedures and rehabilitation. Non-medical codes (n=36,668) accounted for 76% and included places and causes of accidents, place of residence, types of family support, marital status, religion and risk factors (smoking, drinking). Medical codes were further analysed to show main reasons for readmission as below.

Main reasons for readmissions

Five hundred and fifty-one patients (51%) were readmitted from the pool of 1,072 patients over the entire study period, and 8% of ICD-10-AM codes (n=3,876) are assumed to be directly related to SCI, with primary reason depicted in Figure 5.3. See Appendix 5D for the raw data.

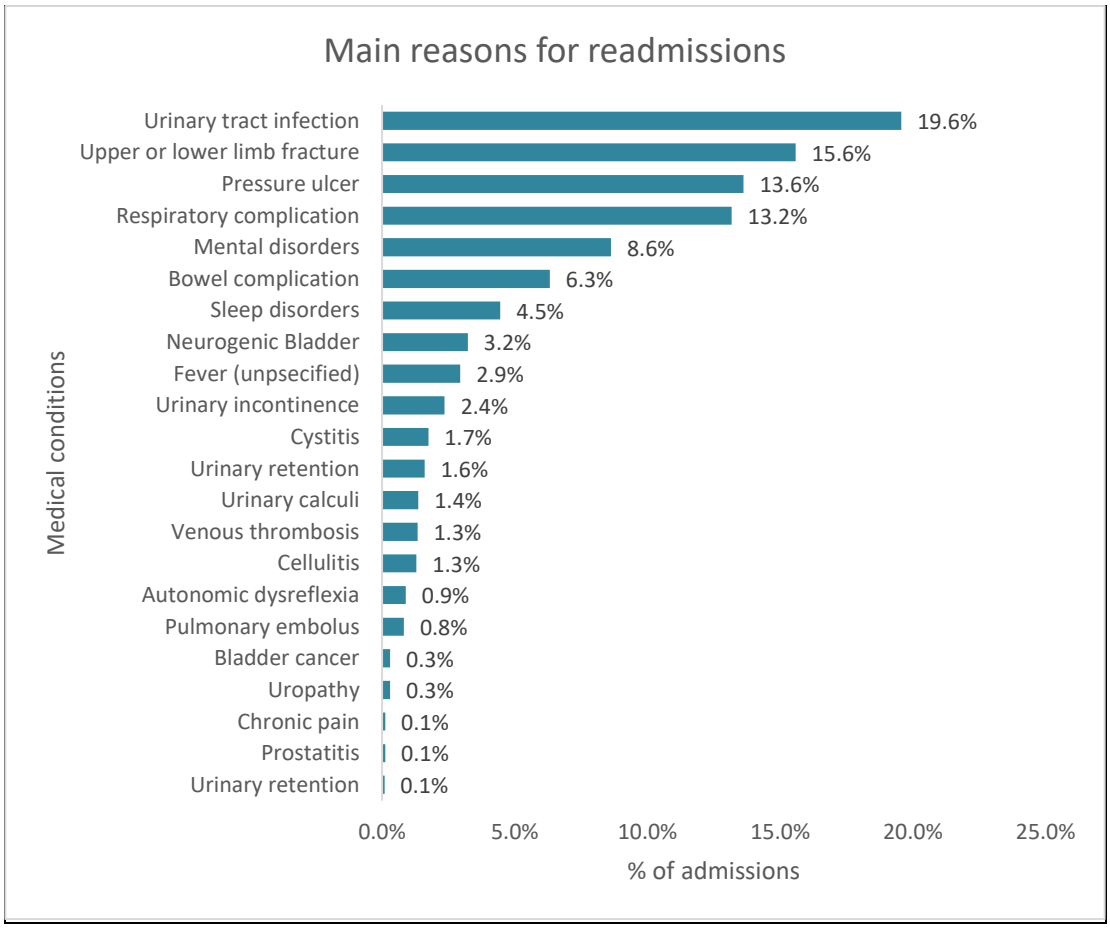


Figure 5-3 Reasons for re-admissions to the Emergency Department

Urinary tract infection was the most frequent reason for readmissions (19.6%), followed by fracture (15.6%). Pressure ulcer, respiratory complication, and mental, bowel and sleep disorders were among the top ten reasons for readmissions.

Number of readmissions

A number of patients had multiple readmissions, ranging from 13 to 18. Overall, 2.2% (12 patients) had more than more than 11 readmissions. As can be seen from Figure 5.4, 34% of patients had one readmission, 15.8 % had two; 23. % had three; 8.3% had four, and 5.3% had five admissions.

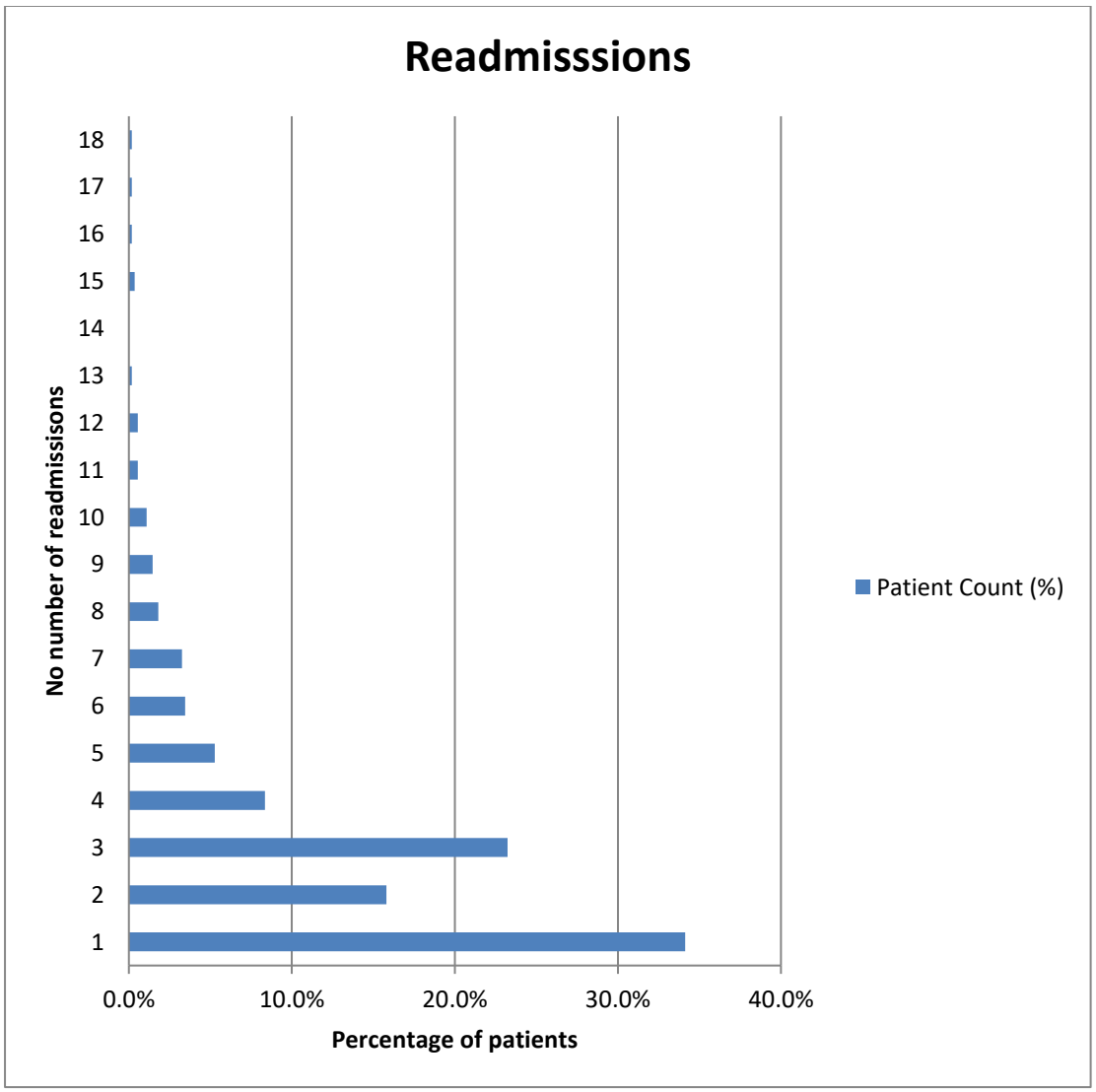
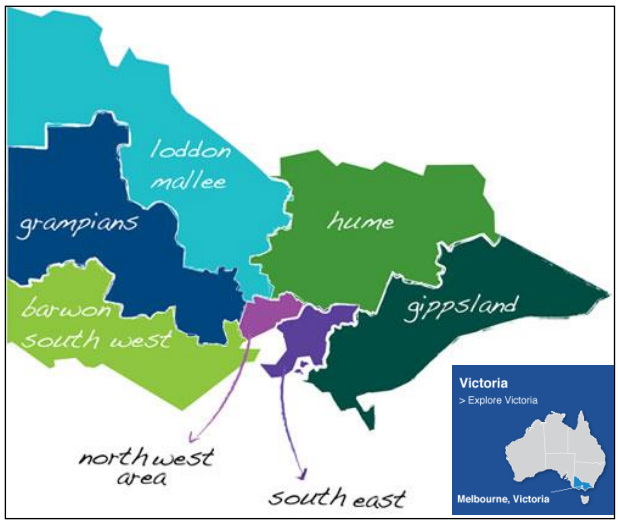


Figure 5-4 Percentage of patients with readmissions

See Appendix 5E for details.

5.5.4 Separation by region

Patients were analyzed according to region of residence in Victoria separated by per capita population. There was higher incidence in the metropolitan area; hence metropolitan regions were further analyzed according to Victorian electorates by locality and postcodes: Inner, Outer, Eastern, Western, and Northern Metropolitan (VEC, 2016) (Figure 5.5, Table 5.2).



Some patients were not resident in Victoria at the time of the accident; there was a high proportion from Tasmania and NSW, and a smaller proportion from Queensland, South Australia, and other states, as well as from overseas.

Figure 5-5 Regions in Victoria

Source: http://www.justice.vic.gov.au

Table 5-2 Separation by Victorian Regions (Health Services)

Separation by Health Services	Total population	Injuries per 100,000	Total No of SCI patients (Male: Female)	% SCI	Male and females per 100,000 & ratio		
					Male	Female	M:F ratio
Gippsland	269,790[5]	39.3	106 (82:24)	9.9	30.4	8.9	3.4:1
Hume	276,300[2]	24.6	68 (60:8)	6.3	21.7	2.3	7.5:1
Grampians	220,875[6]	21.3	47 (38:9)	4.4	17.2	4.1	4.2:1
Loddon Mallee	314,487[3]	19.4	61 (53:8)	5.7	16.9	2.54	6.6:1
Metropolitan*	3,999,982[1]	15.6	625 (516:109)	58.3	14.4	1.2	11.8:1
Barwon-South Western	366,900[4]	13.9	51 (40:11)	4.8	10.9	3.0	3.6:1
Tasmania	515,000	11.7	60 (43:17)	5.6	8.3	3.3	2.5:1
NSW	N/A	N/A	26 (24:2)	2.4	24	2	12:1
Unknown postcodes	N/A	N/A	16 (13:3)	1.5	13	3	4.3:1
Other	N/A	N/A	12	1.1	10	2	5:1
Total			1,072	100.00	879	193	4.6:1

[1](Victorian Places, 2016) [2](Hume Strategy, 2016), [3](Loddon Mallee, 2016) [4](Barwon-South Western, 2016) [5](Gippsland Regional Growth Plan, 2014) *Does not represent full population of NSW. Austin health covers part of South of NSW

Per 100,000 population, the people living in Gippsland region had the highest incidence of injury, followed by Hume, Grampians, Loddon Mallee, Metropolitan and Barwon-South Western regions.

Total number of male and female admissions per 100,000 separated by the health service area and ratio of males to females are shown in Table 5.2. Male and female ratios range from3.4:1in Gippsland and 7.5:1 in Hume; a mean ratio of 4.6:1 was observed in the regions, excluding metropolitan and unknown sources.

A detailed separation by five age ranges and sex are shown in Figure 5-6. Age range and sex for the Metropolitan region is shown separately in Figure 5.7. see Appendix 5F for the raw data.

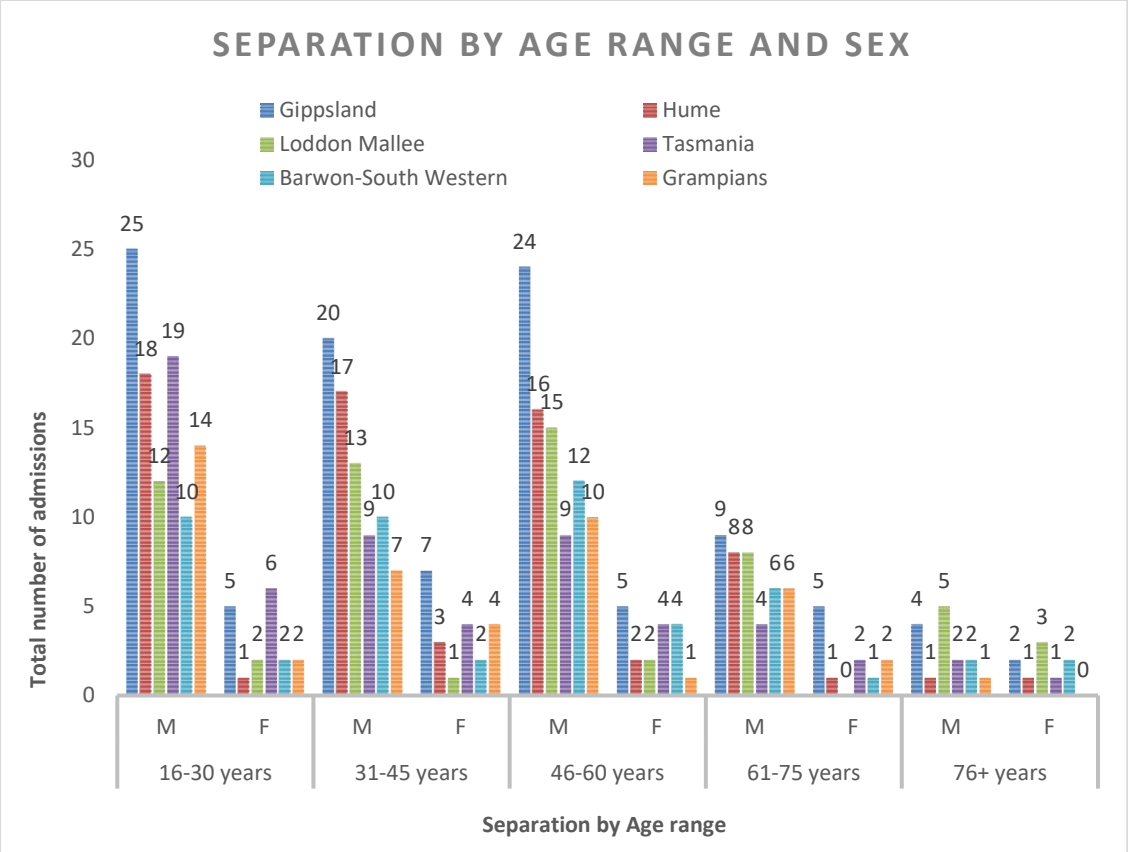


Figure 5-6 Health Services in the regional areas

Gippsland had the highest number of accidents per 100,000 in Victoria. There were more males in all age groups except the 75+ age range. Tasmania recorded the highest number of females injured in the younger age group (n=6) followed by Gippsland (n=5). Gippsland recorded higher numbers of females injured in the 31-45, 46-60 and 61-75 age ranges. However, the overall numbers were small (range from 0 to 9 admissions).

Although the Metropolitan region overall had the highest rate of injuries (15.6 per 100,000), further analysis showed that the Eastern Metropolitan region had the highest rate of injuries (21.2) per 100,000 population, followed by Northern Metropolitan (19.4) South-Eastern Metropolitan (13.4), Western Metropolitan (12.3) and Southern Metropolitan (10.2) regions (Table 5.3).

Table 5-3 Separation by Metropolitan Areas (Injuries per 100,000)

Metropolitan Areas	Total number of SCI patients	Total Population in region	Injuries per 100,000	Total No of SCI male and females		
				Male	Female	Ratio
Eastern Metropolitan	210	988,783	21.2	16.3	5.0	3.3:1
Northern Metropolitan	152	785,000	19.4	17.3	2.0	8.7:1
South-Eastern Metropolitan	63	471,688	13.4	10.8	2.5	4.3:1
Western Metropolitan	88	716,500	12.3	10.6	1.7	6.2:1
Southern Metropolitan	112	1.098,477	10.2	8.4	1.8	4.6:1
Total	625	4,060,448		12.7	2.7	4.7:1

Division by Electoral Boundaries Commission (VEC, 2016)

The ratio of male and female admission in the metropolitan area ranged from 3.3:1 in the Eastern Metropolitan region to 8.7:1in the Northern Metropolitan region; the mean ratio was 5:1.

A graph showing separation by age range and sex in the Metropolitan region is shown in Figure 5.7. Raw data is included in Appendix 5G.

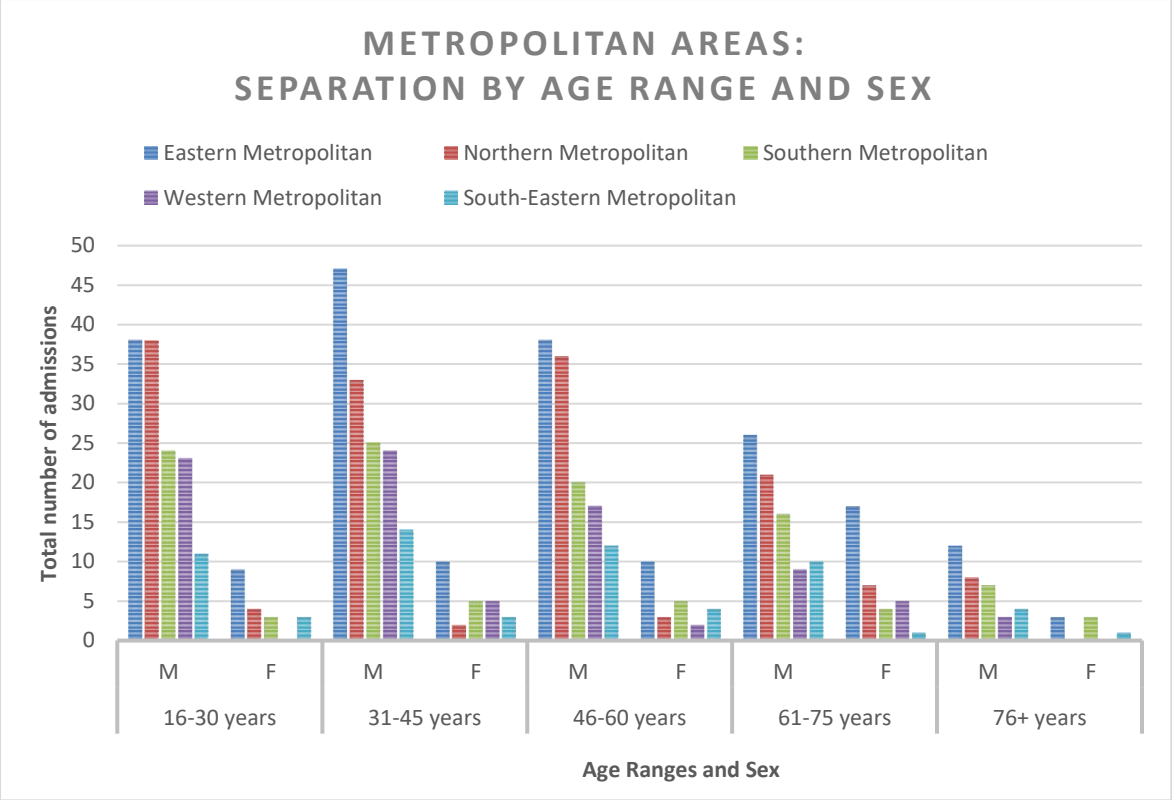


Figure 5-7 Metropolitan areas: age range & sex

The Eastern Metropolitan region recorded the highest number of males injured in the age group of 31-45years. The Northern Metropolitan region had the second highest number of males in all age groups, followed by the Southern, Western and South-Eastern Metropolitan.

The total proportion of females in the Metropolitan areas was 17.4 % (n=109) compared to males (82.6%; n=516). The highest proportion of female admissions was in the age range 61-75 years (31.2%) where half were from Eastern Metropolitan areas. The second highest group of female admissions was in the age range of 31-45 years (23%), with 40% from Eastern Metropolitan areas. The third highest number of female admissions was in the age range 46-60 years (22%), with45% from the Eastern Metropolitan region. The fourth highest number of female admissions were in the age range 16-30 years (17%) with Eastern Metropolitan accounting for 47%. The age range above 76+ represented 6% of the total admissions in females where both Eastern and Southern Metropolitan regions represented 43% each.

5.5.5 Separation by hospital admissions

The Victorian Department of Health and Human Services uses a cost funding model called WIES (Weighted Inlier Equivalent Separation), which is a cost weight that is adjusted for time spent in hospital. Each hospital admission is assigned a WIES value, which is used to calculate resources for care of each patient. The Victorian Government uses this as a basis for an activity-based case mix funding policy for public hospitals and pays hospitals the price per unit of WIES. WIES takes into account differences in specialization, economies of scale and level of remoteness (Victorian Department of health and Human Resources).

Figure 5.8 shows total allocated WIES for the sample, separated by principal diagnosis. For traumatic SCI, excluding the sequelae, the highest WIES allocation (3,616.8 units, mean 108.6 units) was for cervical spinal cord injury at C5 followed by C4 (2,628.2 units, mean 73.7 units) and C6 (2042.7 units, mean 60.8 units).

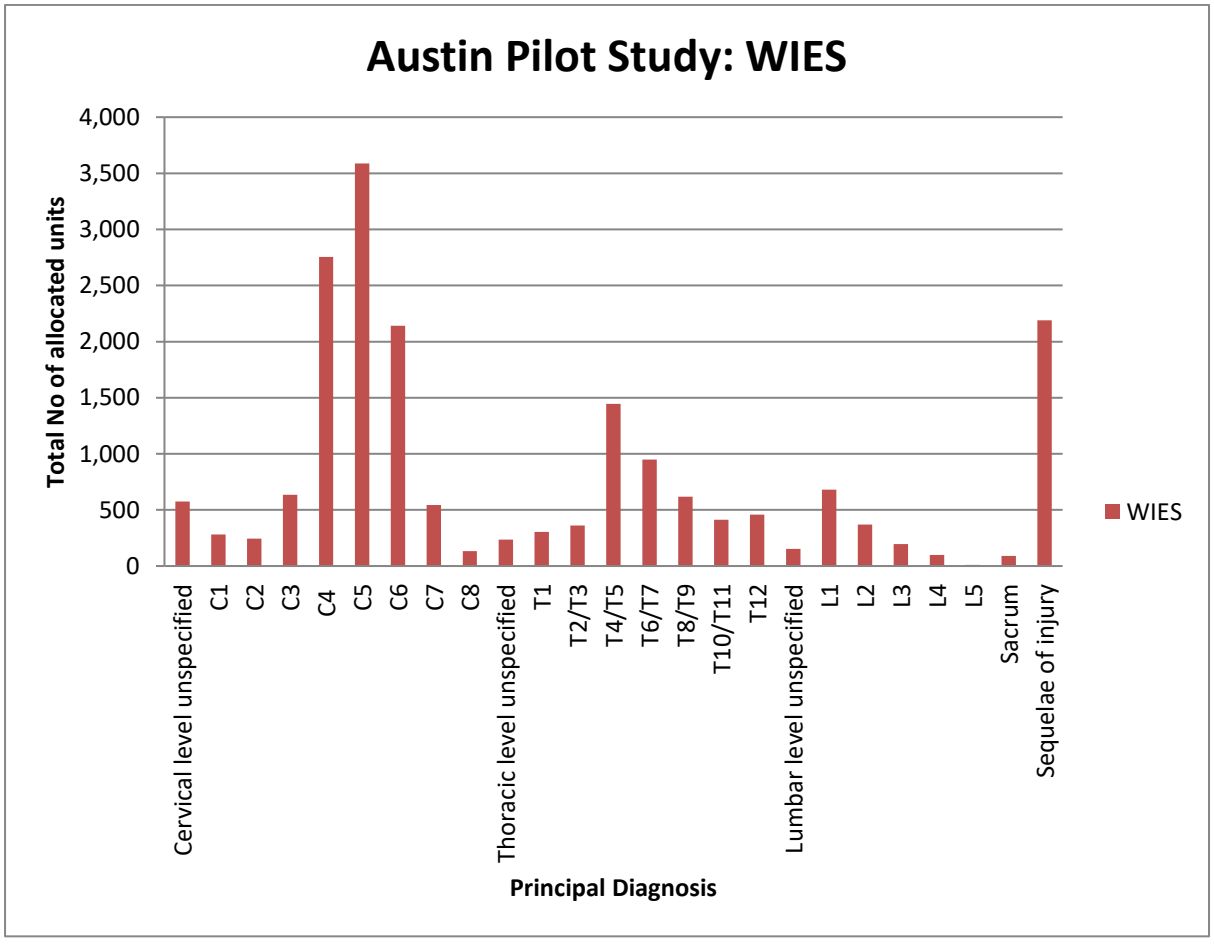


Figure 5-8 separations by WIES, see Appendix 5F for the raw data.

As can be seen in Figure 5.5, patients with injury at the C5 level showed the highest WIES allocation (3,586 units) with substantially higher hospital stays than patients with C4 (8,048) and C6 (6,726) levels of injury. The highest numbers of hospital admissions were for sequelae of injury, however patients admitted for this reason had the lowest average LOS as most of them were in for only days of care, as expected.

5.6 Key Findings

- 1,072 patients were admitted to Austin Health with TSCI over a 10-year period, with female: male ratio of 1:4.6. Male patients aged 16-30 years represented the highest proportion, whilst females were mainly in the 31-45 and 46-60-years age groups.
- Trend analysis in male and female admissions showed a significant increase between 2002 and 2004 which was maintained throughout the study period.
- Separation by principal diagnosis showed that the most common level of injury was C5 followed by C4 and C6.
- From a total of 48,029 readmissions, the ten most frequent reasons for readmission were urinary tract infection, fracture of upper and lower limbs, pressure ulcer, respiratory complications, mental disorder, bowel complication, sleep disorder, neurogenic bladder and fever (unspecific).
- Thirty-four percent of patients had only one readmission, while 2.2% had more than 11 readmissions over the study period.
- From the analysis of patients' residence, most patients were from the metropolitan area. However, when examined as injuries per 100,000, most injuries occurred in Gippsland, followed by Hume, and the Grampians. The Eastern metropolitan region had the highest number of injuries per 100,000 within the metropolitan area.
- The analysis of hospital length of stay showed that patients with C5 level injury had the highest level of hospital stay with matching WIES allocation, while the sequelae of spinal cord injury resulted in a high number of readmissions though the lowest LOS, as most of them were day visits.

5.7 Discussion

The total number of individual patients with SCI identified from our cohort over the period 1998-2008 after data cleansing was 1,072; these patients had a total of 48,029 hospital admission episodes over that period. The higher number of males is consistent with findings in other Australian studies (New et al., 2015) and comparable with those of international studies (DeVivo,

2012). However, the male: female ratio in our study is much higher than that of a one-year study of 77 patients in Finland, where the ratio was 2.1:1 (Koskinen, 2014).

The study was not able to capture the first admissions on all patients, as many were admitted to Austin Health after first being admitted to trauma centres such as Royal Melbourne (n=51) and Alfred Hospitals (n=8). Some patients may have been admitted to other hospitals before they came to the Austin Hospital.

In 2000, the Royal Melbourne, Alfred and Royal Children's Hospitals were officially designated as trauma centres. This led to the establishment of the Victorian State Trauma System with changes in guidelines and admission practices resulting in a significant increase in the number of trauma patients transferred from regional Victoria (VSTR, 2016).

A significant increase in male admissions from 2002 to 2005, maintained throughout the study period, was due to an increase in transfers of patients from the Royal Melbourne and Alfred Hospitals. With both these trauma centres equipped with helipad facilities since 2004 there has been an increased intake of patients with major trauma at these sites (VSTR, 2021). Almost 30% of patients were aged 16-30 years, consistent with previous reports from the Victorian State Trauma Registry (VSTR, 2021), a single-centre study in Latin America (Zárate-Kalfópulos et al., 2016) and other international studies (DeVivo, 2012). However, the majority of females with SCI were aged 31-45 years. The gap between male and female admissions can be seen to be narrowing with age. This trend towards increased numbers of females with SCI among the elderly may continue because injuries among older persons are increasing as women become more active (VSTR, 2021).

Cervical spinal cord injuries at the C5, C4 and C6 levels were the most common reasons for admission to the Emergency Department. Patients with this type of injury are tetraplegic, with the seriousness of injury matched by the highest WIES allocation and longest LOS. The lifetime cost per incident case of SCI is estimated to be $8.5 million for tetraplegia (SpinalCure Australia, 2021). The actual cost per patient is based on the number of WIES, so the relationship between injuries can be identified. This is the first analysis of actual costs of TSCI rather than being based on global estimates.

There were 48,029 readmission episodes from 1,072 patients, equating to an average rate of re-hospitalisation of 2.23%, with major causes being urinary tract infections (UTI), pressure ulcer and respiratory complications. Similar rates have been reported in other studies, with genito-urinary system disorders being the primary reason for readmission in Australia (24.1%), (Middleton et al., 2004) and in the USA (30%) (DeJong, et al., 2013). In our pilot study, in addition to UTI, other reasons for readmission were fracture of upper and lower limbs, pressure ulcer and respiratory infections. We also found a high percentage of sleep disorders (n=210) and depression due to drug and alcohol abuse (n=171) as reasons for readmission, similar to the reports by Berlowitz et al. (2005) and Cripps (2006).

The region where patients resided (Table 5.4 & 5.5) was of interest to us for a range of reasons. It enables the identification of potential factors associated with the accident, e.g. whether it was due to traffic or road safety issues (speed limits or blind spots), or due to work-related issues. This information is highly important for policy development and planning for provision of social and medical support after patients are discharged from hospital. The major limitation of our study was that our data was in the form of postcodes where patients resided rather than where the accidents had actually occurred. If patients were to return to their original postcode of residence after discharge, and given that many are wheelchair-dependent after injury, lack of appropriate transportation may be a major issue, especially if this place is in regional or rural areas where slow health care reform is one of the major barriers (Middleton et al., 2008).

Our analysis of the postcodes per capita (expressed as admissions per 100,000), showed that the highest number of admissions were from regional areas of Victoria, namely Hume and Gippsland. This finding is similar to findings reported by VSTR on overall trauma patients, although not specific to SCI, and may be related to road traffic accidents occurring on major highways traversing these regions with a high number of tourists.

The highest number of patients with SCI was from those residing in the Metropolitan areas, but only the fifth highest per 100,000. In our analysis, patients from the Eastern Metropolitan, followed by Northern Metropolitan and South-Eastern Metropolitan regions, had the highest number of hospital admissions. In contrast to the report by VSTR in the same period, showed that the Northern and Southern Metropolitan areas had the highest hospital admission rates overall for major trauma cases, with a high percentage of assaults (VSTR, 2011). The Eastern Metropolitan region had the highest rate of elderly patients admitted. According to the Victorian Department of

Health and Human Services, the Eastern Metropolitan region has the highest living standard and longevity in Victoria and the percentage of the population aged 65 years and over is expected to grow from 15.5% in 2011 to 18.4% in 2021 (DHS, 2013). This is a very important factor to consider given that the highest percentage of patients came from the Eastern Metropolitan area with predicted longevity and associated secondary conditions. Hence, in line with the growing population and the projected increase in longevity, sensible health planning to support survivors of SCI is needed.

5.8 Limitations

The study focused on adults (age 16+), so does not include patients under 16 years old.

The major limitation of our study was that our data was in the form of postcodes where patients resided rather than where the accidents had actually occurred, and therefore road safety and other factors contributing to road traffic accidents (blind spots, road quality, lights etc) could not be assessed.

Thirty-five per cent of the total admissions were for sequelae, which gives us some insights into reasons for readmission. However, the study was not able to capture the first admission of patients to hospital in 1998, and some of these patients may have had readmissions for sequelae of a SCI that occurred earlier as many came after being at trauma centres such as the Royal Melbourne and the Alfred Hospitals. Some patients may have been admitted to other hospitals before being admitted to the Austin.

5.9 Future studies

This study involved linking ICU datasets with VEMD and VAED, to investigate spinal cord injury admissions to one hospital. To the best of my knowledge this is the first Australian longitudinal retrospective study on the patients with traumatic SCI, over a 10-year period, showing the trends of disease as well as health service utilization.

The Austin Pilot Study was the first stage of a linkage program, which was then extended to two other trauma centres in Victoria to provide a more complete picture of the journey of patients with spinal cord injury (reported in Chapter 6). The pilot study provided more detailed insights into reasons for readmission, which is extremely useful, but it does not provide a complete picture of

patient journey. Data linkage with other trauma centres capturing TSCI from the first admission to follow through readmissions would provide a more comprehensive picture of the journey of patients with SCI.

Chapter 6

Time Series Analysis II: Cohort from three hospitals

6 TIME SERIES ANALYSIS II – COHORT FROM THREE HOSPITALS

6.1 Introduction

This Chapter reports the findings of the retrospective time series analysis of linked datasets for patients with spinal cord injury (SCI) from two trauma services (Alfred Health and Royal Melbourne Hospital) and the Spinal Injuries Unit at Austin Health. The background and methodology are described in detail in Chapter 4 (Section 4.4).

The aims of this study were fourfold:

i. To understand the pattern of disease over time
ii. To identify different risk profiles (high, medium and low) and the intervals for readmission
iii. To understand comorbidities and risk factors
iv. To understand cause of death and associated risk factors

6.2 Setting and Scope

This data linkage study concerned three Victorian hospitals: Austin Health, Alfred Health, and the Royal Melbourne Hospital.

The datasets used in the analysis reported in this thesis were limited to people aged more than 16 years and over during the period from 1st July 2000 to 31st June, 2014, covering 14 years.

6.3 Case Selection

Each hospital provided three internal datasets: Victorian Admitted Episodes Dataset (VAED), Victorian Emergency Minimum Dataset (VEMD) and Australian New Zealand Intensive Care Unit Society – Adult Patients Data (ANZICS-APD) over the period 1st July 2000 till 30th June 2014. The datasets contained information about patients 16 years and older, both males and females of all nationalities, including indigenous populations. From the total of nine datasets, data on 2,629 patients with first admission with traumatic SCI were extracted. Of these, 1,078 patients were from the Austin Hospital, 1,298 from the Alfred Hospital and 253 from the Royal Melbourne Hospital, as shown in the flowchart (Figure 6.1).

This study differs from the Austin Pilot study (Chapter 5), in that it captured patients with SCI from their first admission and followed them over time to investigate co-morbidities and complications.

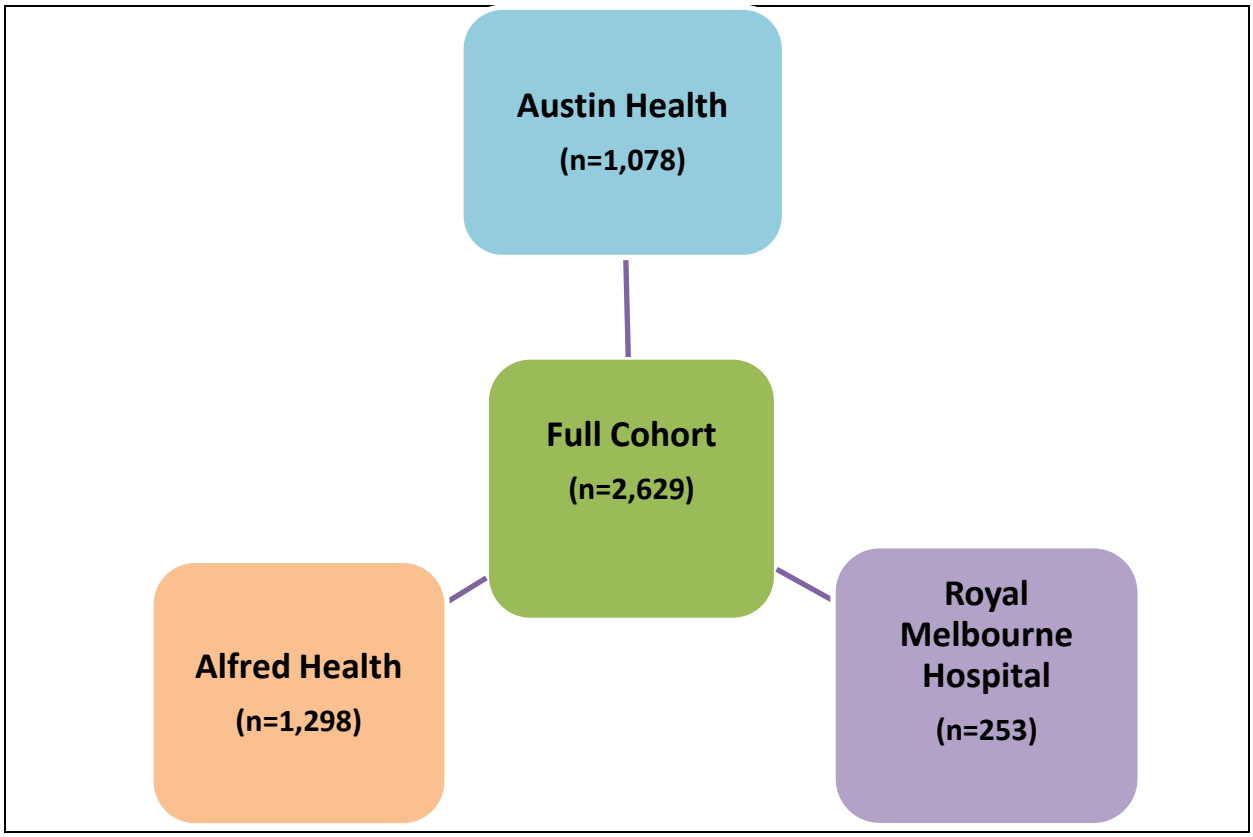


Figure 6-1 Numbers of patients included in the cohort

A list of ICD-10-AM code selection is shown in Table 6.1. Please note the cohort study does not include sequelae unlike in the Austin Pilot study.

These codes were selected after discussion with consultant physicians from the Austin Hospital as well as the Victorian Department of Human Services as per the Austin pilot study.

Table 6-1 List of principal diagnoses for the cohort

ICD-10-AM	Description
S14.0	Concussion & Oedema
S14.1	Other and unspecified injuries of cervical spinal cord
S14.10	Injury of cervical spinal cord, unspecified
S14.11	Complete lesion of cervical spinal cord
S14.12	Central cord syndrome of cervical spinal cord
S14.13	Other incomplete cord syndrome of cervical spinal cord
S14.2	Injury of nerve root of cervical spine
S14.3	Injury of brachial plexus
S14.70	Functional spinal cord injury, cervical level unspecified
S14.71	Functional spinal cord injury, C1
S14.72	Functional spinal cord injury, C2
S14.73	Functional spinal cord injury, C3
S14.74	Functional spinal cord injury, C4
S14.75	Functional spinal cord injury, C5
S14.76	Functional spinal cord injury, C6
S14.77	Functional spinal cord injury, C7
S14.78	Functional spinal cord injury, C8
S24.0	Concussion & Oedema
S24.10	Injury of thoracic spinal cord unspecified
S24.11	Complete lesion of thoracic spinal cord
S24.12	Incomplete cord syndrome of thoracic spinal cord
S24.70	Functional spinal cord injury, thoracic level unspecified
S24.71	Functional spinal cord injury, T1
S24.72	Functional spinal cord injury, T2/T3
S24.73	Functional spinal cord injury, T4/T5
S24.74	Functional spinal cord injury, T6/T7
S24.75	Functional spinal cord injury, T8/T9
S24.76	Functional spinal cord injury, T10/T11
S24.77	Functional spinal cord injury, T12
S34.0	Concussion & Oedema
S34.1	Other injury of lumbar spinal cord [conus medullaris]
S34.2	Injury of nerve root of lumbar and sacral spine
S34.3	Injury of cauda equina
S34.4	Injury of lumbosacral plexus
S34.5	Injury of lumbar, sacral and pelvic sympathetic nerves
S34.6	Injury of peripheral nerve(s) of abdomen, lower back and pelvis
S34.70	Functional spinal cord injury, lumbar level unspecified
S34.71	Functional spinal cord injury, L1
S34.72	Functional spinal cord injury, L2
S34.73	Functional spinal cord injury, L3
S34.74	Functional spinal cord injury, L4
S34.75	Functional spinal cord injury, L5
S34.76	Functional spinal cord injury, sacrum
T09.3	Injury of spinal cord, level unspecified

Austin Hospital – datasets

There was a total of 3, 698 patients with spinal injury in the study period from the three internal datasets (VAED, VEMD and ANZICS-APD). Spinal injury includes all injuries related to the spine, including fractures and dislocations and injury to the spinal cord. Therefore, patients with SCI had to be extracted from these datasets. There were 1,078 patients with SCI extracted from the three internal databases. Of these, 681 patients with SCI were admitted to the ICU with a total of 859 episodes. Patients admitted to ICU did not have ICD codes and post codes, and so this information was extracted through linkage with VAED and VEMD.

In the study period, there were 23,401 episodes of readmission to the Emergency Department (ED).

Alfred Hospital - datasets

From a total of 2,004 patients with spinal injury from VAED and VEMD datasets, data for 1,298 patients with SCI were extracted. The total number of patients meeting our criteria was 1,298 who had 5,465 readmission episodes. Of these patients, 155 were excluded as their first admission was not in the period of study (2000-2014) and subsequent readmissions for these patients were also excluded.

There was a total of 625 patients with SCI admitted to ICU; of these, data for 217 patients who met our criteria were extracted. Length of stay (LOS) in ICU was calculated using admission and discharge dates.

Royal Melbourne Hospital (RMH) - datasets

From a total of 3,260 patients with spinal injury, data for 253 patients with traumatic SCI were extracted from VEMD and VAED datasets between 1st January 2000 and 30th June 2014. There were 4,512 Emergency Department admissions for these patients. Postcodes were not available for 1,186 readmission episodes and were extracted from VAED and ICU datasets to complete the information.

Of the 253 patients, 181 were admitted to ICU at the RMH. From the ICU datasets, it was observed that there were 418 admissions of patients with SCI, and 181 patients had multiple admissions over the period 2000 to 2014. Seventy-two patients admitted to ICU did not have ICD codes. Of

those, 54 were admitted to Austin Hospital and were clinically matched to extract ICD codes. The remaining 18 patients were coded manually from DRG descriptions following the method described in Chapter 4.

6.4 Statistical analysis

A range of statistical analysis was performed using the statistical software package Stata 13 (StataCorp LLC, College Station TX, USA, 2014) and Microsoft Excel (2019).

- Descriptive statistics such as mean, median, standard deviation and Inter Quartile Range (IQR) were applied to describe the population.
- The *t*-test and Pearson chi-squared test were applied to compare continuous variables and binary variables, respectively, with the level of significance defined as $p<0.05$. Fisher's exact method was applied (our sample violated assumptions for chi-squared) to test the difference between male and female deaths.
- Complex statistics such as linear and multivariate regression was performed to investigate the relationship between the Elixhauser Comorbidities Index (risk factors), age, gender, ICU LOS and death.

6.5 Results

Data for a total of 2, 629 patients with TSCI admitted to the three hospitals were analysed.

6.5.1 Separation by Sex and Age Range

There were 1,979 (75.3%) males and 650 females (24.7%) in the cohort, a male: female ratio of approximately 3.2:1 (Table 6.2).

Table 6-2 Separation by Sex and Age Range

Age Range (years)	Male	%	Female	%	Total	Total %
16-30	595	30.1%	133	20.5%	728	27.7%
31-45	454	22.9%	132	20.3%	586	22.3%
46-60	390	19.7%	132	20.3%	522	19.9%
61-75	336	17.0%	123	18.9%	459	17.5%
76+	204	10.3%	130	20.0%	334	12.7%
Total	1979	100.0%	650	100.0%	2629	100.0%

Table 6.2 shows a similar distribution of males and females across age categories. The largest proportion of male patients with SCI were aged between 16-30 years (30.1%) and there was

decreasing incidence with age. However, female patients with SCI were evenly distributed between age groups, with a small dip in the 61-75-year age range.

There was a strong association between age and gender, with male patients being younger than females (r=0.9; p<0.001). Overall, 53% of male patients were <45 years of age compared to 40.8% of the female patients.

6.5.2 Separation by Sex and Age Range by hospitals

Trends in male and female admissions at the three different hospitals were examined. The trends in male admissions were similar in all three hospitals except for a slight difference in the 61-75 years age group at RMH (Table 6.3).

Table 6-3 Separation by sex and age range by hospitals

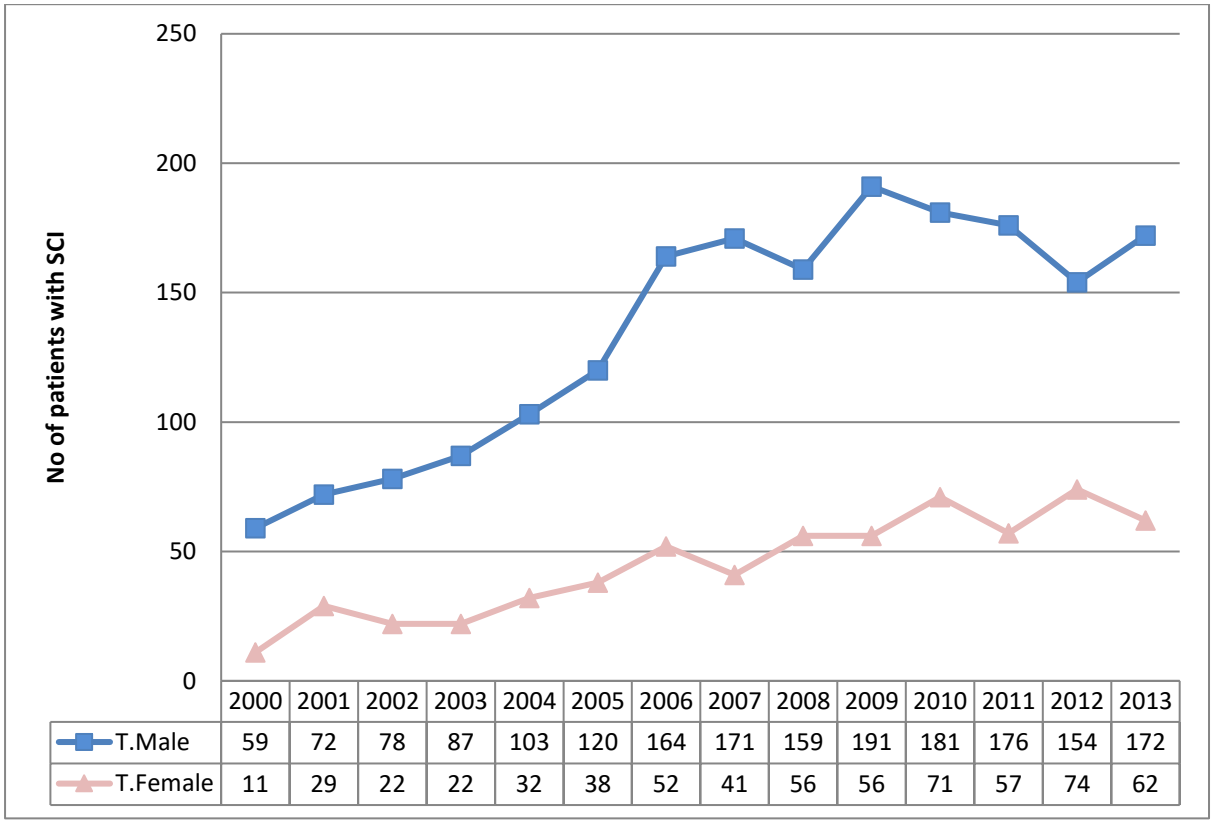
Age	Austin		Alfred		RMH		Total	
Range	Male	Female	Male	Female	Male	Female	Count	%
16-30	297	50	240	71	58	12	728	27.7%
31-45	195	49	216	68	43	15	586	22.3%
46-60	169	36	191	80	30	16	522	19.9%
61-75	136	49	161	63	39	11	459	17.5%
76+	63	34	121	87	20	9	334	12.7%
Total	860	218	929	369	190	63	2629	100.0%

However, the age distribution for female admissions was uneven. At the Austin Hospital, the largest proportion of female patients was in the 16-30 years age range (22.9%), whereas at the Alfred Hospital the largest proportion was in the 76+ year age range (23.6%), and in the 46-60 years age range (25.4%) at the Royal Melbourne Hospital. However, the difference in numbers between the age groups was negligible.

There was a decrease in admission with increasing age in males across the Austin (57.2% vs 45.4% p<0.001) and Alfred Hospitals (49.0% vs 37.7%, p<0.001), but not at RMH (53.2% vs 42.9%, p>0.1).

6.5.3 Trends in admissions by sex

Figure 6.2 shows total trends in admissions by sex from the three hospitals from 2000 to 2013.



	2000	2001	2002	2003	2004	2005	2006	2007	2008	2009	2010	2011	2012	2013
T.Male	59	72	78	87	103	120	164	171	159	191	181	176	154	172
T.Female	11	29	22	22	32	38	52	41	56	56	71	57	74	62

Figure 6-2 Trends in male and female admissions over 14 years

The number of admissions increased over time, but was more apparent between 2000 and 2006. There was a larger increase in male admissions than female admissionsThe annual rate of increase was 16.3% (95% CI: 12.4-20.2) for males and 18.9% (95% CI: 11.7-26.0) for females, which stabilized after 2006 for males.

Detailed trends in admissions by sex from the three hospitals are shown in Figure 6.3.

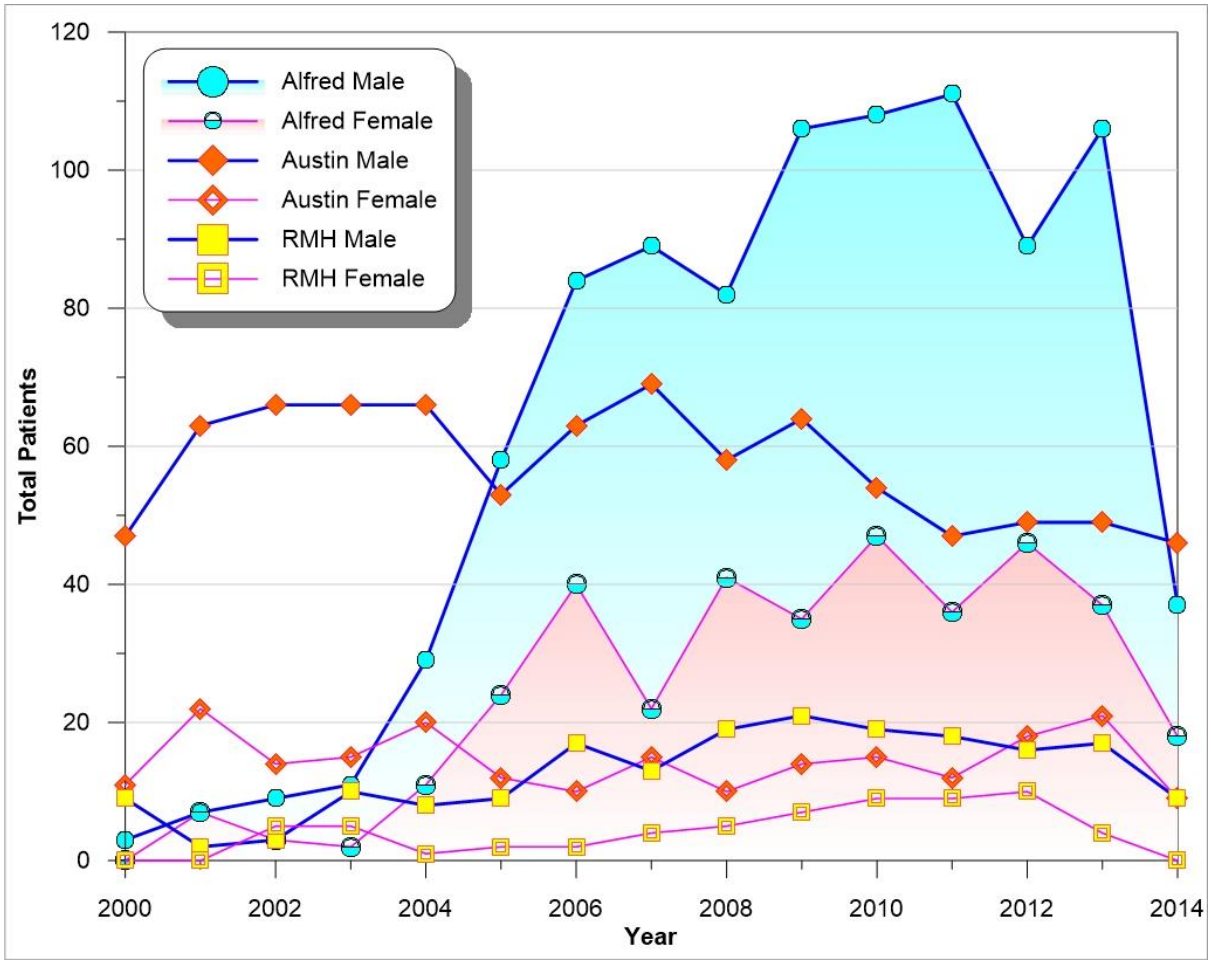


Figure 6-3 Trends in admissions by sex for the period of 2000-2014 from the three hospitals

It should be noted that there was an increase in admissions of patients after the helipad was installed at the Alfred and Royal Melbourne Hospitals, which would have removed patients from regional hospitals; the trend in admissions at the Austin Hospital remained static because all patients from the Alfred Hospital, RMH, and regional hospital would still have been transferred to the Austin site.

A jump in male admissions was observed between 2003 and 2006 for the Alfred Hospital (highlighted with blue shading in Fig 6.3). A consistent rate of 10% in male admissions was observed for RMH from 2003. There were notable changes in total numbers of patients at the Austin and Alfred Hospitals. Female admissions were more erratic due to low total numbers.

6.5.4 Separation by Regions

Analysis of patients admitted to the Austin, Alfred and Royal Melbourne Hospitals according to the area of residence is shown in Table 6.4. Per 100,000 population, the Gippsland region had the highest number of patients with SCI, followed by the Hume, Grampians, Barwon-South Western, Loddon Mallee, Metropolitan regions, and Tasmania. The Metropolitan region had the highest number of patients admitted (54.5%), followed by Gippsland (12.1%), Hume (6.8%), Barwon-South Western (6.7%), Grampians (5.2%) and Loddon Mallee (5.1%). There were admissions of patients from NSW (3.2%), as well as Tasmania (3.5%). Regions with fewer than 10 patients were included in the "Other" category (1.4%), and some patients did not have post codes (1.5%) (Table 6.4).

Table 6-4 Separation by Regions: Injuries per 100,000 population

Separation by Regions	Total number of SCI patients	Total %	Total 0Population	Injuries per 100,000
Gippsland	319	12.1%	269.790[5]	118
Hume	178	6.8%	276,300[2]	64
Grampians	136	5.2%	220,875[6]	62
Barwon-South Western	177	6.7%	366,900[4]	48
Loddon Mallee	134	5.1%	314,487[3]	43
Metropolitan	1434	54.5%	3,999,982[1]	36
Tasmania	91	3.5%	515,000	18
NSW	85	3.2%	N/A	N/A
Unknown	39	1.5%	N/A	N/A
Other #	36	1.4%	N/A	N/A
Grand Total	**2629**	100.0%		

Regions with fewer than 10 patients were included in "Other" (NT, 1; SA, 5; Queensland 3 patients)
[1](Victorian Places, 2016). [2](Hume Strategy, 2016). [3](Loddon Mallee, 2016). [4](Great South Coast, 2016). [5](Gippsland Regional Growth Plan, 2014). *Does not represent full population of NSW, which has its own trauma centres.

The Metropolitan area was further analyzed as it had a very high incidence of SCI (n=1,434). As the metropolitan area is densely populated and with new divisions, electoral boundaries were used to separate postcodes (Table 6.5).

Table 6-5 Separation by Metropolitan Areas

Region	Total No of Patients	Total Population	Injuries per 100,000
Northern Metropolitan	256	471,688	54
Eastern Metropolitan	370	988,783	37
Southern Metropolitan	369	1,098,477	34
South Eastern Metropolitan	221	716,500	31
Western Metropolitan	218	785,000	28
Total	1,434	4,060,448	

Total population of Melbourne: 4,087,000; Division by electoral boundaries commission (VEC, 2016)

Per 100,000 population, the Northern Metropolitan region had the highest rate of injuries (54), followed by the Eastern Metropolitan (37) Southern Metropolitan (34), South Eastern Metropolitan (31), and Western Metropolitan regions (28).

6.5.5 Separation by Principal Diagnosis

Data extracted for patients with traumatic SCI included 44 principal diagnoses (ICD). These ICD codes were sorted into block codes according to cervical (S14.x), thoracic (S24.x), lumbar (S34.x) and T09.3 for SCI unspecified.

Injuries to the cervical spinal cord affected the highest number of patients (n=1,365; 51.9%) (S14.x); 861 patients (32.8%) had injuries to the thoracic spinal cord (S24.x), 396 patients (15.1%) had injuries to the lumbar spinal cord (S34.x), and 7 patients (0.3%) had injuries of the spinal cord, level unspecified (T09.x). This is shown graphically in Figure 6.4.

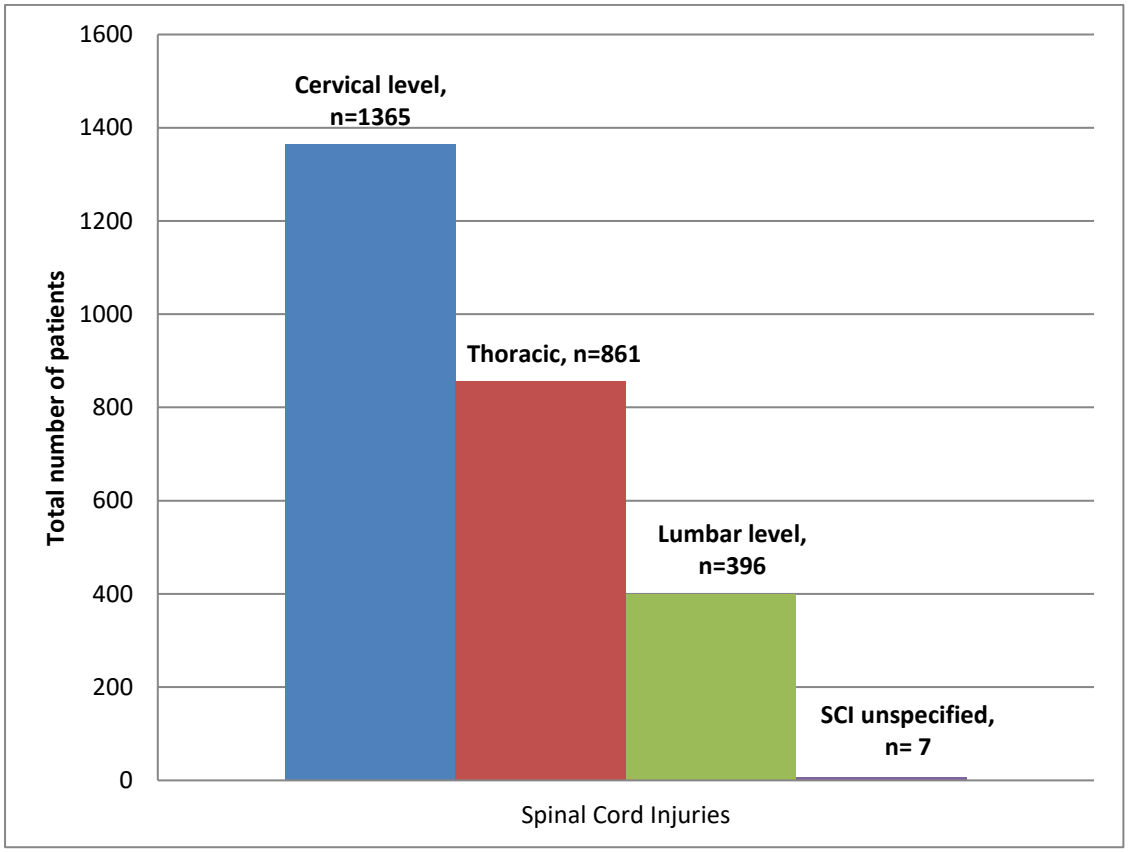


Figure 6-4 Separation by principal diagnosis - block code

The breakdown of individual principal diagnoses is shown in Figure 6.5, see Appendix 6A.

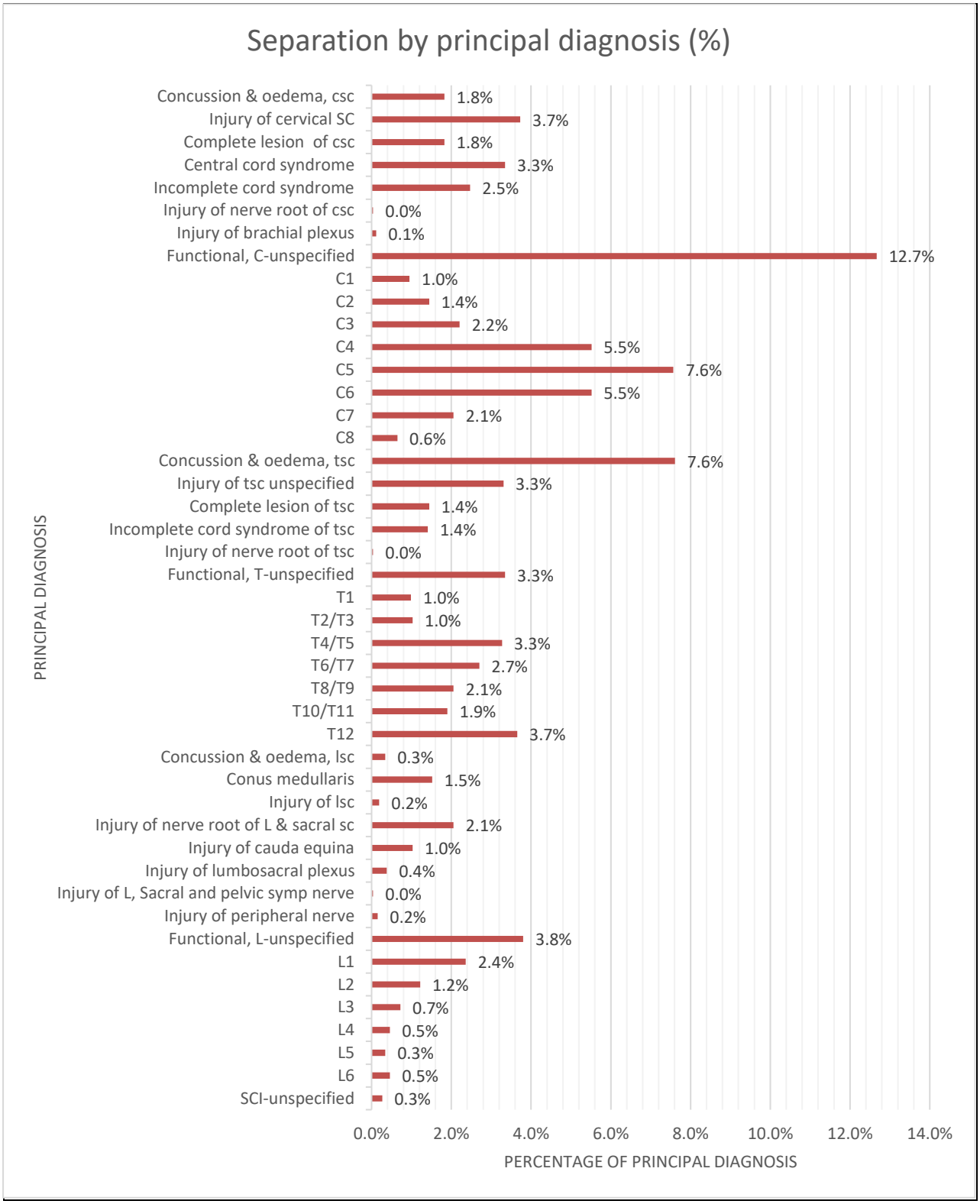


Figure 6-5 Separation by principal diagnosis 2000-2014, (Appendix 6B)

csc: cervical spinal cord; tsc: thoracic spinal cord; lsc: lumbar spinal cord; T: thoracic; L: lumbar; S: sacral; sc: spinal cord. See the Appendix 6B for detail.

As explained in Chapter 2, patients can only have the neurological level of SCI classified when they are stable enough to cooperate with assessment. If patients cannot be fully classified but have functional injuries, they will be classified under cervical, thoracic, and lumbar functional unspecified, respectively.

For those patients who had the neurological level of injury classified (C1-7; T1-12; L1-5), C5 was the most common level (7.6 %, n=199), followed equally by C6 and C4 (5.5%, n=145). Most thoracic level injuries were at T12 (3.7%, n=96), followed by T4/T5 (3.3%, n=86). At the lumbar level, the most common injury was at L1 (2.4%; n=62), followed by L2 (1.2%, n=32).

Within the whole cohort, functional cervical spinal cord injury unspecified had the highest incidence (12.7 %, n=333), followed by concussion and oedema, thoracic (7.6 %, n=200) and functional cervical injury C5 (7.6%, n=199). The patients with initial principal diagnosis of functional spinal cord injury unspecified (cervical, thoracic and lumbar) were reclassified once they were well enough to be assessed properly.

6.5.6 Separation by readmissions

The prospectively maintained database of 2,629 patients with SCI admitted to the three hospitals from mid-2000 to mid-2014 was merged with VAED, VEMD and ICU hospital registry data to identify all readmissions after discharge from the admission for the initial traumatic injury based on discharge dates.

As described in Chapter 4, the information relating to readmissions was collected from several databases and the records were linked using several techniques when combining data from the three hospitals. A unique key using surname and date of birth was created for accuracy (Chapter 4).

The selection from the three hospitals including hospital transfers and deaths from each hospital is shown in Figure 6.6.

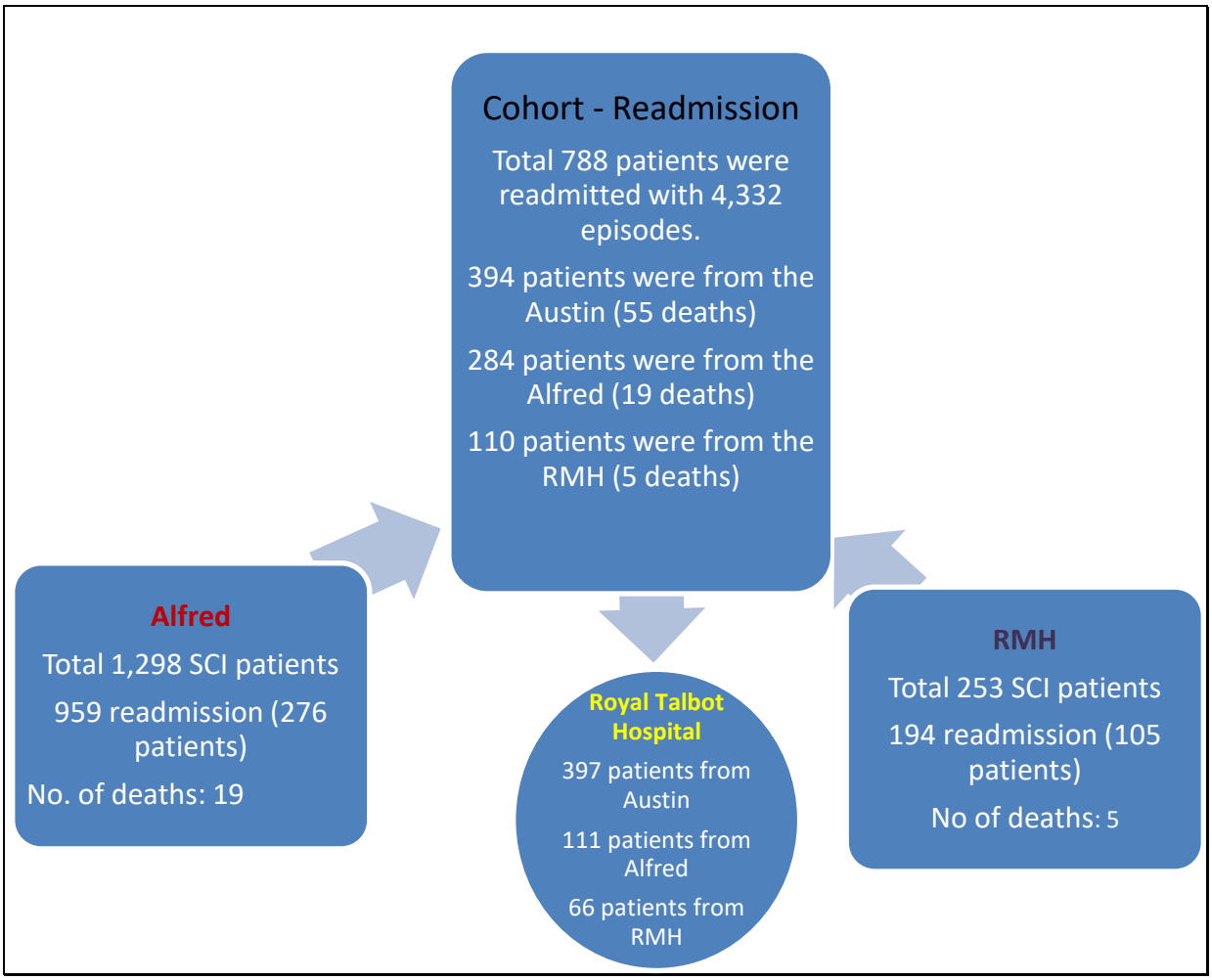


Figure 6-6 Diagram of data extraction for readmissions

The total number of deaths was 79 (55 from Austin, 19 from Alfred and 5 from RMH).
From the Austin Hospital, 574 patients were sent to Royal Talbot Hospital for rehabilitation.

Cohort: Main reasons for readmissions

From a total of 4,332 episodes of readmissions (788 patients), 78,205 individual ICD-10 codes were extracted, and these codes were separated into medical (13.8%, n=10,812) and non-medical (86.2%, n=67,393) codes. All medical codes were then matched to individual principal diagnoses and sorted into cervical, thoracic, and lumbar levels using block codes. The top 15 major reasons for readmission are shown in Figure 6.7.

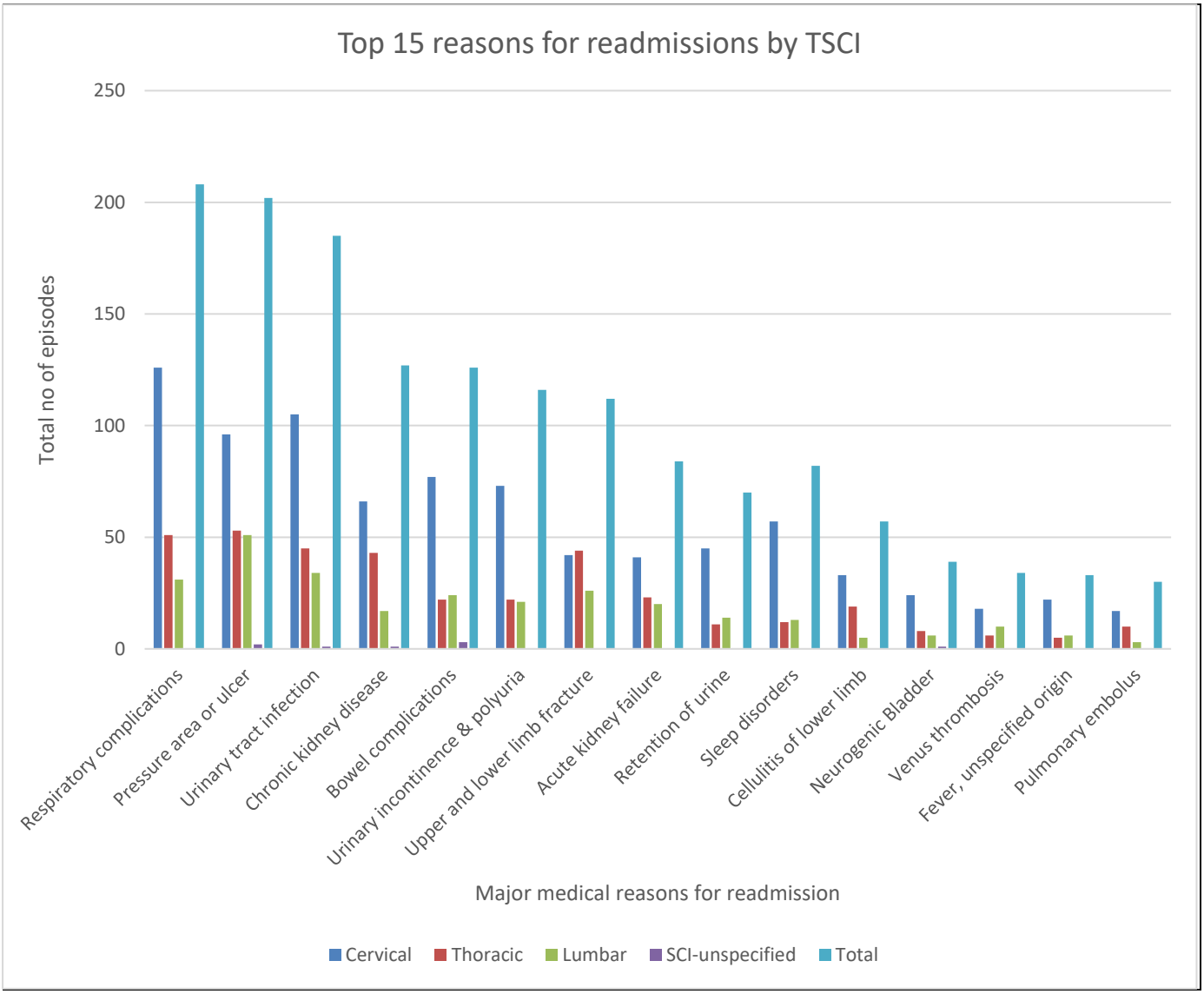


Figure 6-7 Top 15 reasons for readmission by block code

The most common reasons for readmission in the cohort were respiratory complications (pneumonia and pulmonary collapse n=208, 15%), pressure ulcer (n=202, 12.7%) and urinary tract infection (n=185, 11.6%). Patients admitted with acute kidney failure or pulmonary embolism were moved to ICU.

The majority of readmissions were in people with cervical SCI. The most common reason for readmission was respiratory complications (n=126) for those with cervical level injury, whereas pressure ulcer (n=53) was the most common reason for readmission in those with thoracic (n=53) and lumbar (n=51) level injury.

Main reasons for readmission according to principal diagnosis

The following three graphs illustrate in more detail the main reasons for readmission for each of the three principal diagnoses.

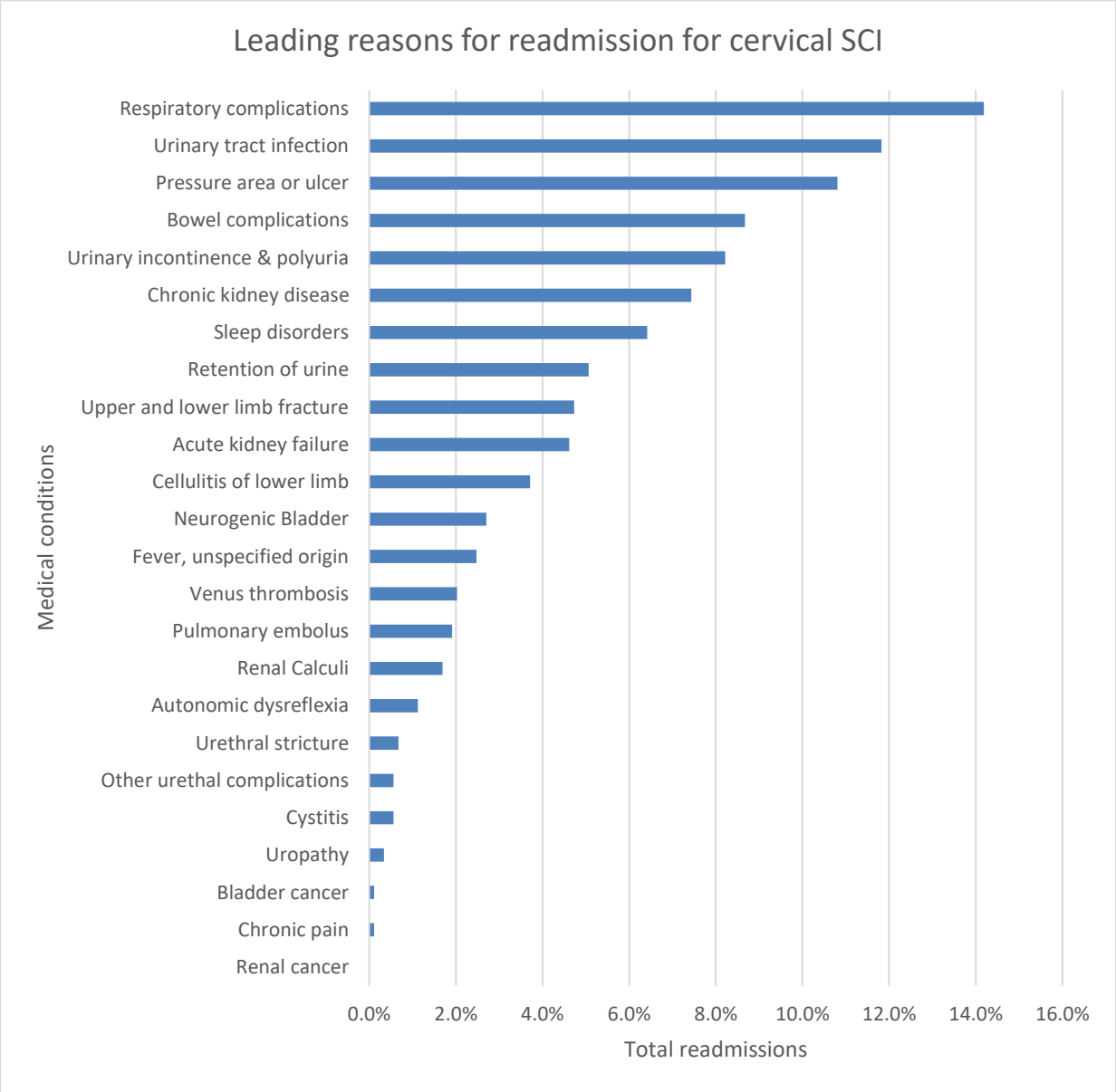


Figure 6-8 Readmissions in patients with cervical SCI (S14.x)

There were 1,365 patients (51.9% of the whole cohort) with a principal diagnosis of cervical SCI (S14.x). The most common reasons for readmissions with cervical SCI were respiratory complications (n=126, 14.2%), urinary tract infection (n=105, 11.8%), pressure areas (n=96, 10.8%), bowel complications (n=77, 8.7%) and urinary incontinence (n=73, 8.2%).

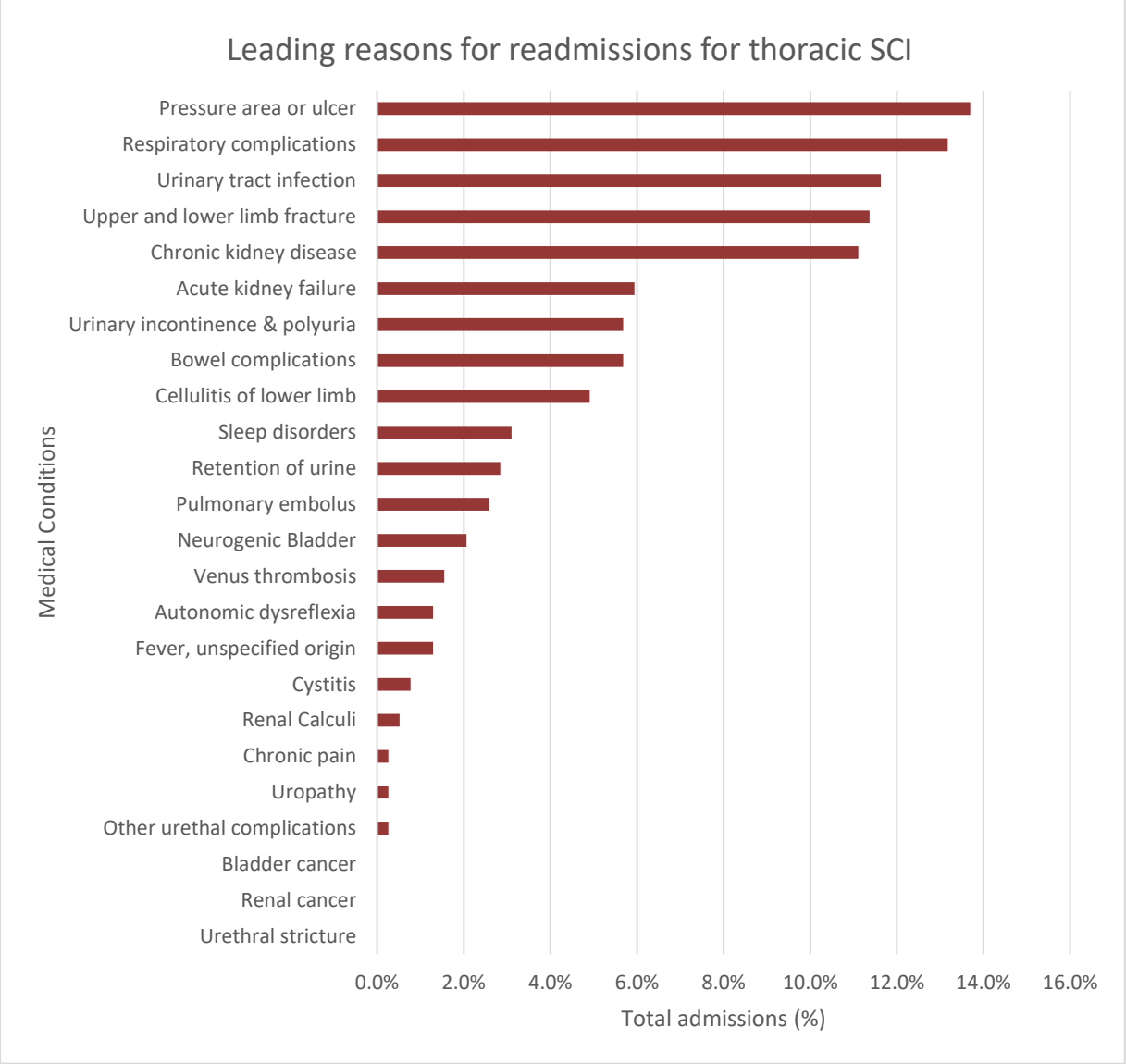


Figure 6-9 Readmission in patients with thoracic SCI (S24.x)

There were 861 patients (32.7% of the total cohort) admitted with a principal diagnosis of functional thoracic SCI (S24.x). The most common reasons for readmission were pressure ulcer (n=53, 13.7%), respiratory complications (n=51, 13.2%), urinary tract infection (n=45, 11.6%), fracture (n=44, 11.4%) and chronic kidney disease (n=43, 11.31%).

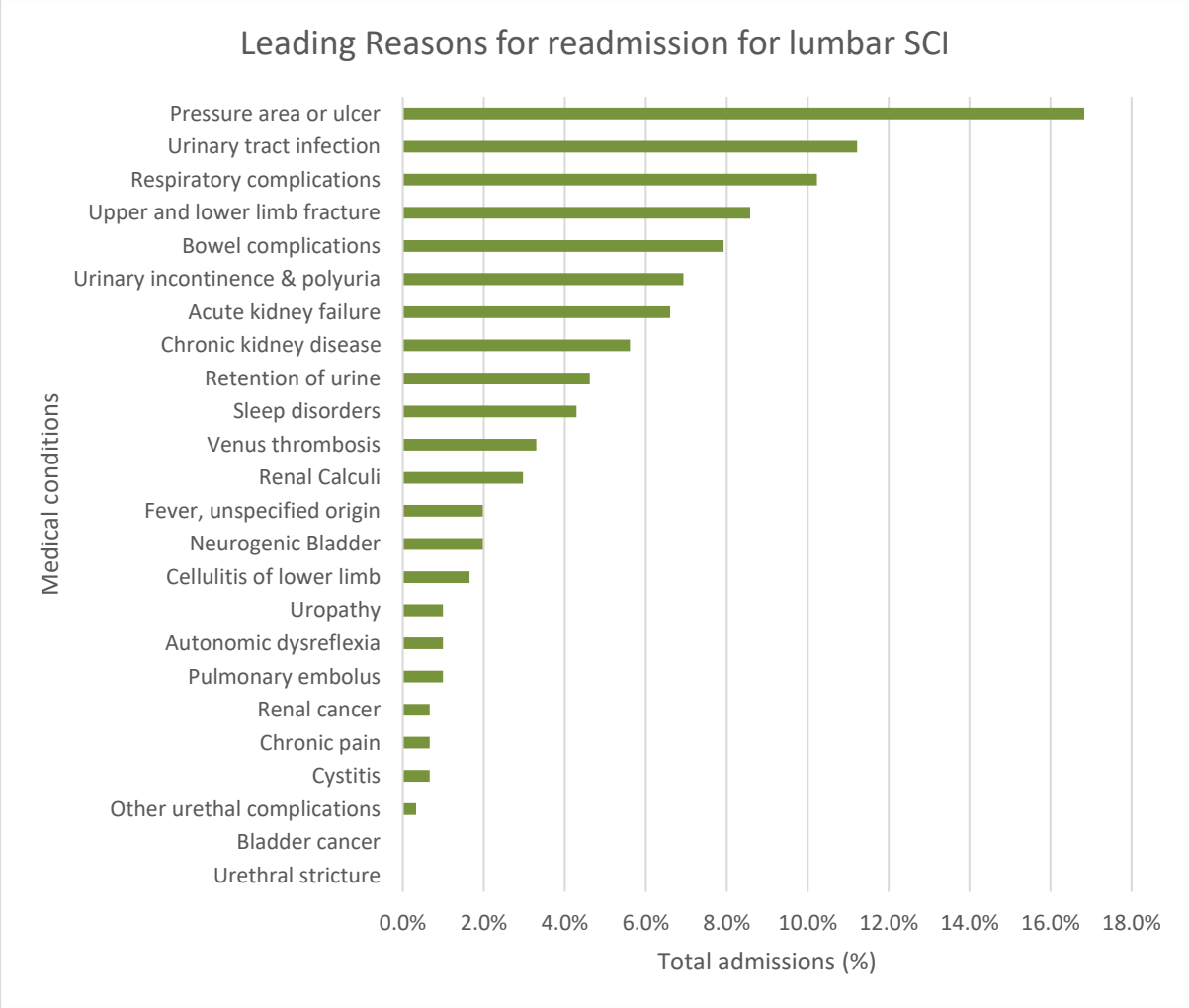


Figure 6-10 Readmission in patients with lumbar SCI (S34.x)

Three hundred and ninety-six (15.1% of the total cohort) patients were admitted with lumbar SCI as the principal diagnosis. The most common reasons for readmission were pressure ulcer (n=51, 61.8%), urinary tract infection (n=34, 11.2%), respiratory complications (n=31, 10.2%), fracture (n=26, 8.6%) and bowel complications (n=24, 7.9%).

There were seven patients with principal diagnosis of spinal cord injury unspecified in the cohort. Ten readmissions were noted and these were due to pressure ulcer (2 episodes), bowel

complications (3 episodes), urinary tract infection (1 case), and four cases of urethral complications (urethral stricture, neurogenic bladder).

Patients with SCI at all levels had a high number of readmissions for pressure ulcer, urinary tract infection, respiratory complications, bowel complications, sleep disorders, upper and lower limb fracture and sleep disorders.

Percentage of readmissions

The number of readmissions for patients in this cohort ranged from 1 to 18 times (Figure 6.11). Seventy-nine patients died during the 14-year study period.

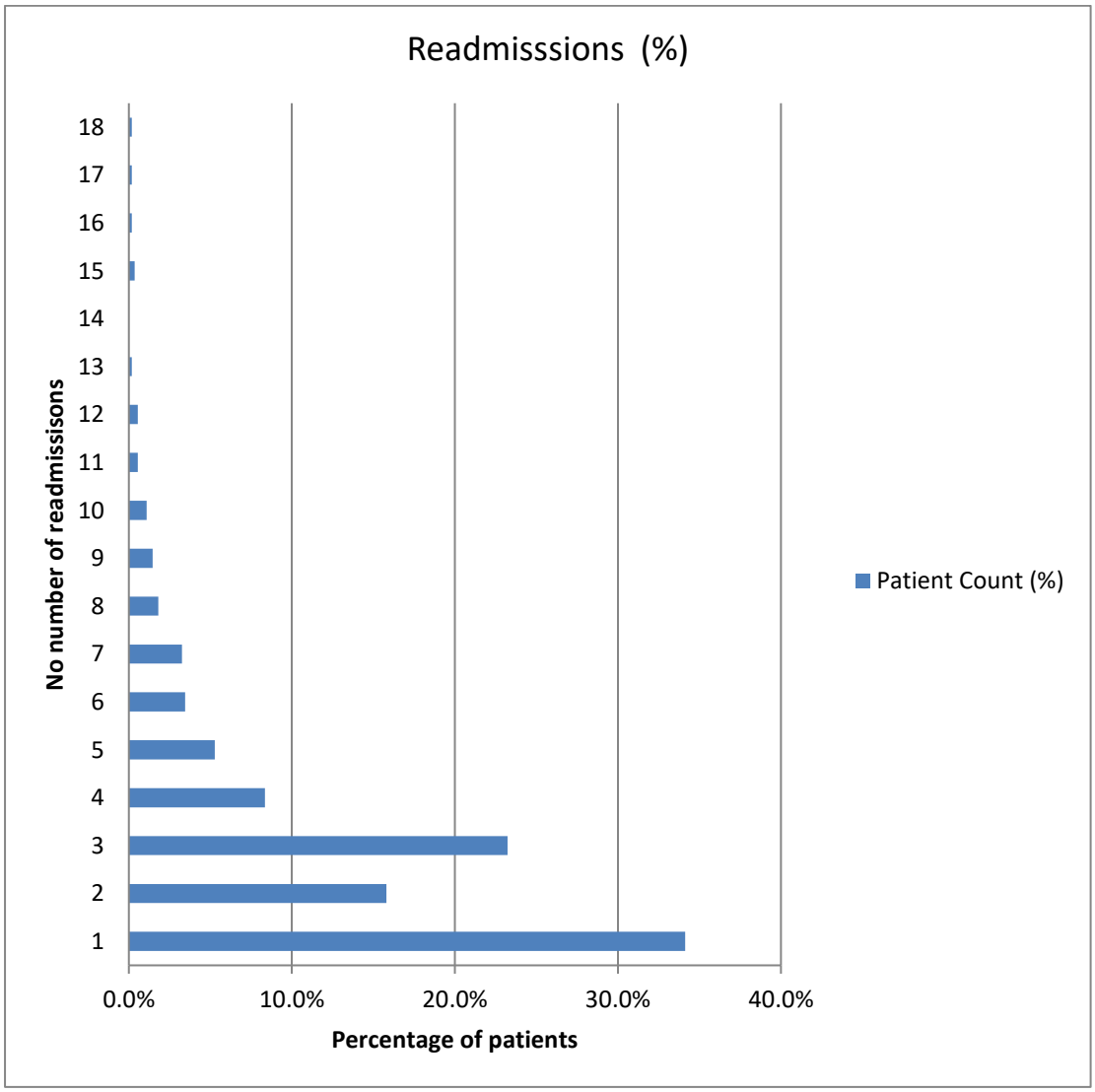


Figure 6-11 Percentage readmissions (see Appendix 6B for details)

Most patients (34%) had only one readmission. A number of patients had multiple readmissions: 15.8 % had two, 23. % had three, 8.3% had four, and 5.3% had five admissions. However, 2.2% (12 patients) had more than more than 11 readmissions. One patient was admitted 56 times over two years due to weekly kidney dialysis, an obvious outlier who was not included in the analysis.

6.5.7 Separation by length of stay (LOS) in ICU

Length of stay (LOS) in ICU for all SCI groups was analysed and validated against hospital discharge summaries. LOS was calculated from care unit admission and discharge dates for 1,220 patients (46.4%) from our cohort who had an ICU admission. The total LOS by principal diagnosis is illustrated in Figure 6.12. See Appendix 6C for raw data.

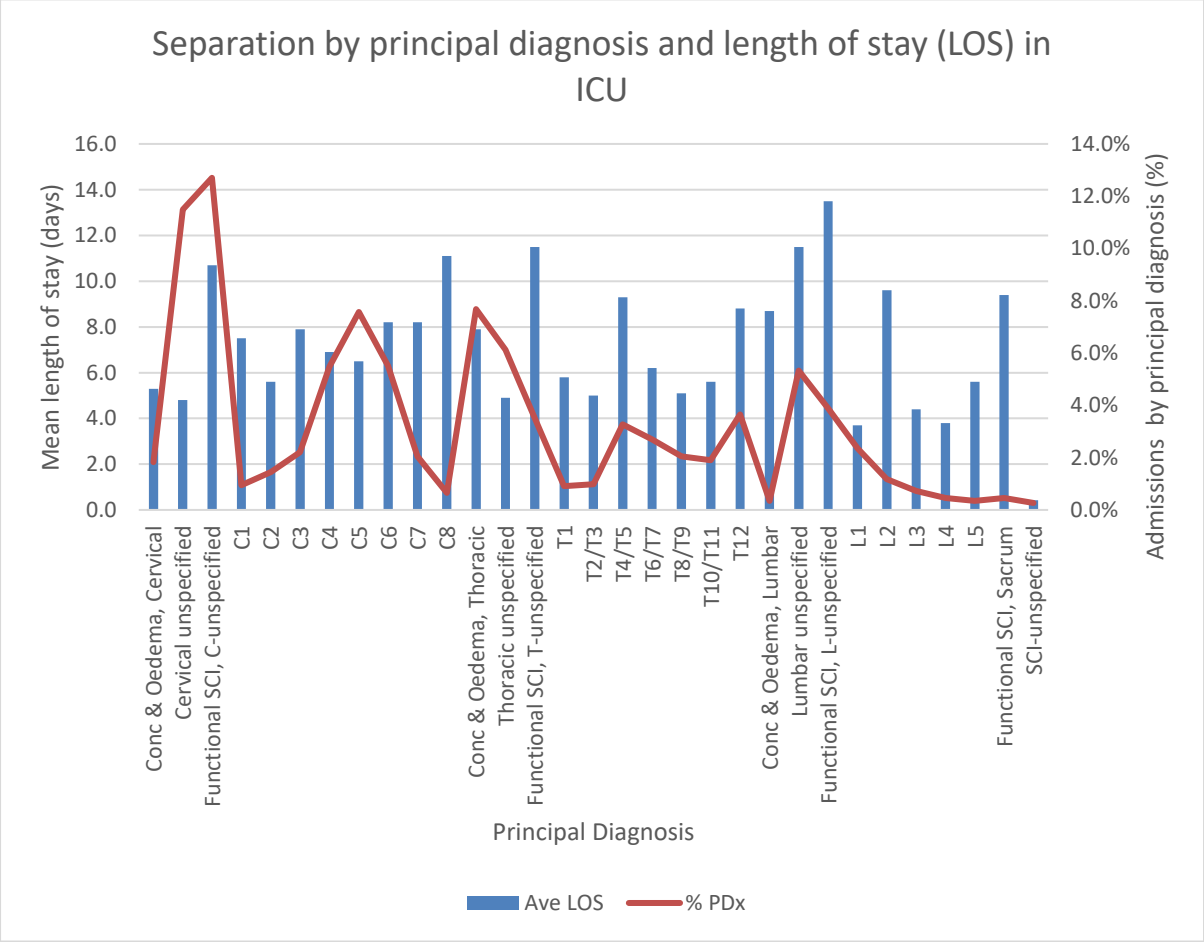


Figure 6-12 Mean length of stay by principal diagnosis, see Appendix 6C for details.

Patients with SCI at the cervical level were those most commonly admitted to ICU (51%) and had the highest total length of stay in ICU (total LOS 82.7 days, mean 7.5 days), followed by thoracic SCI (32.8%; total LOS 70.1 days, mean 7.0 days) and lumbar **SCI** (15.1%; total LOS 52.1 days, mean 7.8 days). Median (IQR) and mean (SD) LOS were calculated (Table 6.6).

Table 6-6 Median (IQR) and mean (SD) for LOS in ICU for patients with cervical, thoracic and lumbar SCI

SCI level	Median (days)	IQR	Mean (days)	SD
Cervical	7.4	2.1	7.3	1.3
Thoracic	6.4	3.3	6.6	1.7
Lumbar	4.6	3.4	5	1.9

Although patients with cervical SCI had the highest median LOS, and patients with lumbar SCI had the lowest median LOS, the IQR of 3.4 days for this group indicates the highest variability in LOS among the three groups.

6.5.8 Comorbidities and Length of Stay (LOS) in ICU

The association between comorbidities and length of stay (LOS) in different age groups was investigated.

There was a total of 28 ICD-10-AM codes denoting comorbidities, and those included in the analysis were:

- Blood pressure: orthostatic hypotension (I95.x), hypertension (I10.x)
- Cancer: lung (C34.x), skin (C44.x), breast (C50.x), prostate (C61.x), neoplasm of renal pelvis (C65.x), malignant neoplasm of brain (C71.x), lymph node (C77.x), malignant neoplasm of bone (C79.x), neoplasm of digestive system (C78.x), diffused large B-cell lymphoma (C83.x), non-Hodgkins lymphoma (C85.x), multiple myeloma (C90.x), blood cancer (C91.x)
- Metabolic disorder: thyroid disorder (E03.x), type I-DM (E10.x) & type II-DM (E11.x), obesity (E66.x), thyroid disorder (E07.x)
- Mental disorder: schizophrenia (F20.x), depression (F30.x-F33.), phobia & anxiety disorder (F40.x), other anxiety disorder (F41.x), acute stress reaction (F43x.), eating

disorder (anorexia nervosa- F50.x), paranoid personality disorder (F60.x), behavioral disorder child and adolescent onset (F98.x)

- Neuropathy: hereditary idiopathic neuropathy (G61.x), cerebral palsy (G80.9)
- Infectious disease: carrier of viral disease (Z22.2), carrier of bacterial disease (Z22.3)
- Dementia & Alzheimer (F00.x)
- Tinnitus (H93.1)

Two well-known comorbidities indices, Charlson and Elixhauser, were considered (See the appendix 4E, 4Fa & 4Fb). The hospital-based Elixhauser Comorbidity Index was chosen for the analysis. In addition, ten more comorbidities that are specific to spinal cord injury were added (rows 31-40), see the Appendix 4Fb.

As outlined in Ch 4, the extended Elixhauser Comorbidity Index (ECI) was calculated for all participants; 1,766 (67.2%) scored 0, and 95.1% had a score <=3. Overall, the ECI for this cohort ranged between 0 and 12 with median (IQR) of 0 (0-1). In general, there was a mild positive correlation between ECI and overall LOS in ICU (rho = -0.17, $p<0.001$) and age (rho = 0.16, $p<0.001$).

The results of multilevel gamma regression show that an increase in ECI led to a significant increase in overall LOS (B= 0.23, 95% CI 0.20 – 0.26, $p<0.001$), while controlling for age, gender, ICU LOS and clustering effect of the admitting hospital. Males had a risk of death 2.1 times higher than females.

6.5.9 Time Series Analysis: Risk Profile

From the studies of readmissions and the intervals at which they occurred; it was possible to provide risk profiles for each case. The following examples are of patient journeys after SCI, from the initial injury to readmissions over the study period.

Patients were categorized into three categories to generate risk profiles:

- High (21 to 56) readmissions, 22 patients (3.1%)
- Medium (11-20) readmissions, 48 patients (6.8%)
- Low (1-10) readmissions, 633 patients (90%)

There were 22 patients (3.1% of the total cohort) who were readmitted more than 21 times, 48 patients (6.8%) admitted 11 to 20 times and 633 patients (90%) admitted 1 to 10 times. An example of a patient from three categories is shown below to show the granularity of the data. Full details of all patient journeys can be seen in Appendix 6D.

Risk profile: High readmissions

An 83-year-old male who was diagnosed with injuries to thoracic spinal cord (S24.0) had pre-existing conditions of anaemia & cardiac implant device. Cancer was recorded at the 51st readmission, 3 years after the initial trauma. The first readmission was 2.4 years after first discharge. He was readmitted 50 times with intervals of 2 to 3 days with soft tissue disorder, pressure ulcer and varicose veins in the lower extremities.

Table 6-7 Risk profile: High readmissions

51 readmissions: 83-year-old male
Total period of time examined: (Oct 2011 – Dec 2014)
Principal diagnosis: Injuries to thoracic spinal cord (S24.0).
Comorbidities: Anaemia, and cardiac implant device. Cancer recorded at the 51st readmission, 3 years after the initial trauma.
Risk factors: None recorded

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
20-Oct-11	**10-Nov-11**			**S24.0**
07-Apr-14	11-Apr-14	2.4 years	5	Radiology procedure (5), soft tissue disorder (5) & varicose veins lower extremities with ulcer (5)
14-Apr-14	17-Apr-14	2.4 years	4	Radiology procedure (4), soft tissue disorder (4) & varicose veins lower extremities with ulcer (4)
22-Apr-14	24-Apr-14	2.5 years	3	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
28-Apr-14	30-Apr-14	2.5 years	3	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
01-May-14	02-May-14	2.5 years	2	Pressure ulcer, soft tissue disorder, varicose veins lower extremities with ulcer
05-May-14	09-May-14	2.5 years	5	Pressure ulcer, soft tissue disorder, varicose veins lower extremities with ulcer
12-May-14	16-May-14	2.5 years	5	Pressure ulcer (5), soft tissue disorder (5), varicose veins lower extremities with ulcer (5)
19-May-14	23-May-14	2.5 years	5	Radiology procedure (5), soft tissue disorder (5) & varicose veins lower extremities with ulcer (5)
26-May-14	30-May-14	2.5 years	5	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
02-Jun-14	06-Jun-14	2.6 years	5	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
10-Jun-14	13-Jun-14	2.6 years	4	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
17-Jun-14	20-Jun-14	2.6 years	4	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
03-Nov-14	16-Dec-14	3.1 years	1	B-cell lymphoma, atrial fibrillation and flutter & varicose veins lower extremities with ulcer

Number in the bracket (e.g. 5), indicates number of times patient was admitted with medical condition; e.g. 'radiology procedure (5)' means that the patient was admitted five times for radiology procedure.

Risk profile: Medium readmissions

A 26-year-old male, with complete lesion of thoracic spinal cord (S24.11) and functional level thoracic T12 (S24.77) with no comorbidities and risk factors. The main reasons of readmission over six years and five months were cellulitis, neurogenic bladder, pressure ulcer, urethral stricture and urinary retention.

Table 6-8 Risk profile: medium readmissions

20 readmissions: 26-year-old male
Admission Period: (Jan, 2008 – May, 2014)
Principal diagnosis: Complete lesion of thoracic spinal cord (S24.11) & Functional level thoracic T12 (S24.77)
Comorbidities: None recorded
Risk factors: None recorded

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
27-Jan-08	**13-Mar-08**			**S24.11 & S24.77**
09-Apr-08	20-Aug-08	6 months	1	Constipation (1), fever unspecified (1), Sleep apnoea (1) & venous thrombosis (1)
27-Sep-08	12-Feb-09	1 year	7	Abnormal head movement (1), Autonomic dysreflexia (2), constipation (1), flatulence of unknown origin, respiratory complication (1), sleep apnoea (1) & UTI (5)
06-Aug-10	08-Feb-11	3 years	2	Abdominal pain (1), Autonomic dysreflexia (1), respiratory infection (1), Sleep apnoea (1)
09-Jan-12	13-Jan-12	4 years	2	Autonomic dysreflexia (1), constipation (1), Sleep apnoea (1) & UTI (2)
25-Mar-12	30-Dec-12	5 years	5	Autonomic dysreflexia (1), constipation (1), respiratory complications (2), Sleep apnoea (1) & UTI (2)
20-May-13	24-May-14	6 years	4	Acute upper respiratory tract infection (1), Autonomic dysreflexia (1), bowel complications (1) & UTI (2)

Risk profile: Low readmissions

Ninety per cent of patients (n=655) were readmitted between one and 10 times over the study period; 15 patients were readmitted ten times, 21 patients nine times, and other readmissions ranged from 32 patients being readmitted eight times to 213 patients readmitted once only. Below is an example of a typical SCI patient with 9 readmissions.

Table 6-9 Risk profile: Low readmissions

9 readmissions: 22 years, Male. **Principal diagnosis:** Incomplete cord syndrome of cervical spinal cord (S14.13) & functional spinal cord injury, C6 (S14.76) **Comorbidities:** hypotension **Risk factor:** none				
Admission Date	**Discharge Date**	**Cumulative Interval**	**Admission No**	**Reasons for readmission**
26-Jan-12	**9-Feb-12**	**First admission**		S14.13 S14.76
9-Feb-12	11-Feb-12	1m	3	UTI, care involving use of rehab procedure
11-Feb-12	11-Feb-12			Other cervical disc disorders, Cervicalgia
20-Feb-12	20-Feb-12			Care involving use of rehab procedure
26-Jun-12	26-Jun-12	6m	3	Urinary calculi
26-Jul-12	26-Jul-12			Other cervical disc displacement, Cervicalgia
31-Jul-12	31-Jul-12			Pressure ulcer
03-Sep-12	03-Sep-12	1year	3	Rectal prolapse
01-Oct-12	01-Oct-12			Pressure ulcer
01-Nov-12	01-Nov-12			Pressure ulcer

Data extraction of separation by principal diagnosis, age range and sex are shown in Appendix 6D(c).

6.5.10 Intervals

The pattern of readmissions was investigated at the following intervals post-discharge: 1 month, 3 months, 6 months, 1 year and annually up to 11 years. The main reasons for readmission separated by intervals are shown in Figure 6.13. A summary of all patients, episodes, and ICD-10-AM codes extracted from the readmission is shown in Table 6.10.

The intervals from one month to 11 years are color-coded. As can be seen in Figure 6.13, UTI, pressure ulcer, mental disorders, respiratory complications, bowel complication and sleep apnoea are prominent in the first month (blue), and three (red) and six months (green) post-discharge.

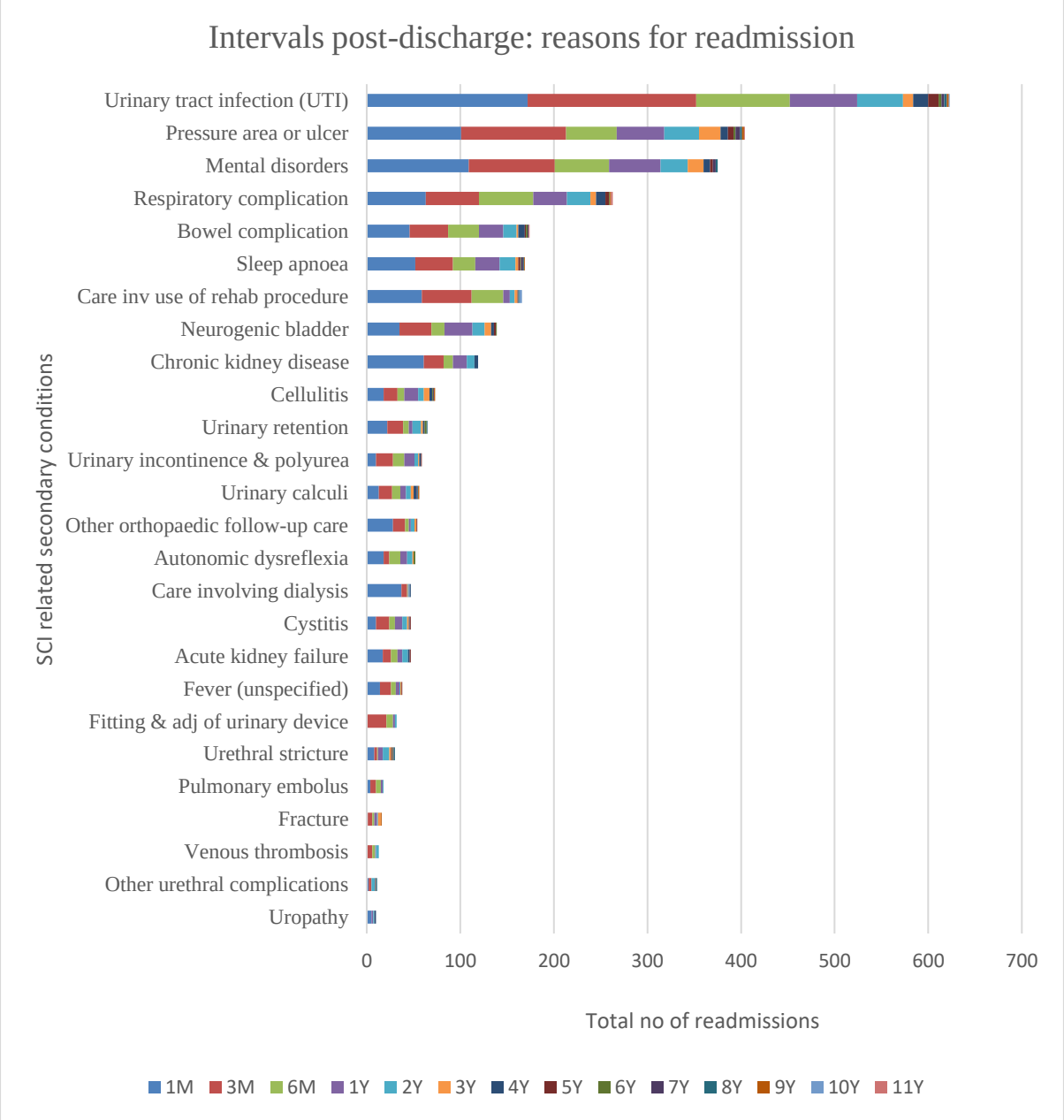


Figure 6-13 Separation by intervals: reasons for readmission
(see Appendix 6E for details)

A summary of detailed readmissions by intervals and reasons are shown in Table 6.8.

Table 6-10 Summary of reasons for readmission

SCI-related secondary conditions	1M	3M	6M	1Y	2Y	3Y	4Y	5Y	6Y	7Y	8Y	9Y	10Y	11Y	**Total**
Urinary tract infection	172	180	100	72	49	11	16	11	3	3	3	2	1		623
Pressure area or ulcer	101	112	54	51	37	23	8	6	2	5	2	2		1	404
Mental disorders	109	92	58	55	29	17	7	3		3	2				375
Respiratory complication	63	57	58	36	25	6	10	4	1			1		2	263
Bowel complication	46	41	33	26	14	2	7	1	2	1				1	174
Sleep apnoea	52	40	24	26	17	3		2	1	2	1	1			169
Rehabilitation procedure	59	53	34	7	5	3		1			1		3		166
Neurogenic bladder	35	34	14	30	13	7	3	2	1						139
Chronic kidney disease	61	21	10	15	8		4	0							119
Cellulitis	18	15	7	15	6	6	3		1	1		1			73
Urinary retention	22	17	6	4	9	2	2		2		1				65
Urinary incontinence	10	18	12	11	4	1	2	1							59
Urinary calculi	13	14	9	6	5	3	3			1	1	1			56
Orthopaedic follow-up	28	13	4	2	4	2		1							54
Autonomic dysreflexia	18	6	12	7	6	1			2						52
Acute kidney failure	17	9	7	5	6		2	1							47
Cystitis	10	14	6	8	5	2	1	1							47
Care involving dialysis	37	6	1	1	1		1								47
Fever (unspecified)	14	12	5	4	1	1		1							38
Fitting & adj of urinary device		21	7	2	2										32
Urethral stricture	8	3	1	5	7	2		1	1	1	1				30
Pulmonary embolus	4	6	5	2	1										18
Fracture	1	5	2	3	1	3						1			16
Venous thrombosis		6	3	1	3										13
Urethral complications	2	3			4			1			1				11
Uropathy	5			2	1		2								10
SCI related ICD-10-AM codes	905	798	472	396	263	95	71	37	16	17	13	9	4	4	3100

[M=months; Y=Year]

Four hundred and six patients were readmitted in the first month post-discharge, 430 patients at 3 months post-discharge, 291 patients at 6 months, 233 patients at 12 months and 165 at 2 years or more post-discharge. A significant drop in readmissions was noted after 2 years (93 patients). The main reasons for readmission were UTI (19%), mental disorder (12%) and pressure ulcer (11%).

Details of readmissions at each time-point post-discharge at one month, three months, six months, twelve months and two to 11 years with SCI secondary related conditions are shown in Appendix 6F (a to n).

Below is an example of readmissions at 12 months separated by reason for readmissions.

Table 6-11 Readmission after 12 **months post-discharge**

Total: 233 patients; 397 episodes, 396 SCI related ICD-10-AM codes		
Medical description	**Count**	**%**
Urinary tract infection	72	10.4
Mental disorders	55	8.0
Pressure area or ulcer	51	7.5
Respiratory complication	36	5.3
Neurogenic bladder	30	4.4
Sleep apnoea	26	3.8
Bowel complication	26	3.8
Chronic kidney	15	2.2
Cellulitis	15	2.1
Urinary incontinence & polyuria	11	1.6
Cystitis	8	1.1
Autonomic dysreflexia	7	1.0
Care involving use of rehab procedure unspecified	7	1.0
Urinary calculi	6	0.8
Acute kidney failure	5	0.7
Urethral stricture	5	0.7
Urinary retention	4	0.6
Fever (unspecified)	4	0.6
Pulmonary embolus	2	0.3
Fracture	3	0.3
Fitting and adjustment of urinary device	2	0.3
Uropathy including hydronephrosis	2	0.2
Venous thrombosis	1	0.1

A total of 233 patients were readmitted after 12 months post-discharge from the initial admission; 397 episodes recorded, and 396 SCI-related codes were isolated for the analysis. UTI accounted for 10.4% of total episodes, followed by mental disorders (8.0%) and pressure ulcer (7.5%).

UTI, pressure ulcer and mental disorder were the top three reasons for readmission until the 8th year post-discharge. At the ninth year, UTI and pressure ulcer were the main two reasons. At the tenth year, UTI and care involving rehabilitation were the only two reasons for readmission. At the 11th year, there were two episodes of respiratory complications, and one readmission for pressure ulcer and bowel complication. From the 8th year onwards, the total number of patients being readmitted reduced dramatically to 10 or fewer as shown in Table 6.8.

6.5.11 Risk Factors

All risk factors for the patient cohort were recorded and analyzed. They were broadly in three groups:

- Alcohol: alcohol dependent (F10.x) & (Z72.2)
- Smoking: tobacco (Z72.0)
- Drug: mental and behavioral disturbance due to opioid (F11.x), cannabis (F13.x), other stimulant (F15.x) multiple stimulants (F19.x), drug use (Z72.2)

The total number of risk factors was inversely proportional to age, with the two youngest age groups having the highest total number of risk factors.

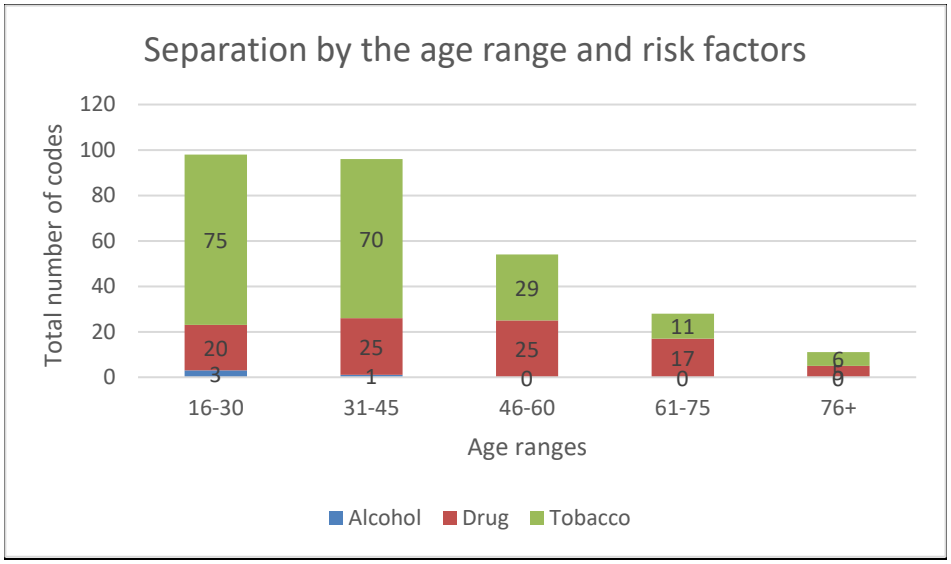


Figure 6-14 Separation by age group and risk factors

(see Appendix 6G for the raw data)

Alcohol dependency was higher in the 16–30-year age group (n=3) compared to the 31-45 age group (n=1). Illicit drug use was recorded in all age groups, with lowest in the 76+ year age group (r=0.73, p=0.03). Use of tobacco was prominent in the earlier age groups and there was a significant reduction in tobacco use from the age of 46 years onwards. There was a strong correlation between age and tobacco use (r=0.96, p<0.001), with a high percentage of smokers in the two younger age groups: 16-30 (77%) and 31-45 (73%).

6.5.12 Deaths

Death data were available for the Austin Health patients only (n=79). Over the study period 79 patients died. The sex, the age range and principal diagnosis of the patients are shown in Table 6.12.

Table 6-12 Separation by death

Age Range	16-30		31-45		46-60		61-75		76+		Total Patients
Sex	F	M	F	M	F	M	F	M	F	M	
Complete lesion of cervical spinal cord (S14.11)						2		2		1	5
Central cord syndrome cervical (S14.12)							1		1	3	5
Other incomplete cord syndrome cervical spinal cord (S14.13)				1				1			2
Functional spinal cord injury cervical unspecified (S14.70)								1			1
Functional spinal cord injury, C1 (S14.71)					1			1		1	3
Functional spinal cord injury, C2 (S14.72)		2				3				1	6
Functional spinal cord injury, C3 (S14.73)						2		3			5
Functional spinal cord injury, C4 (S14.74)				1		3		4	1	5	14
Functional spinal cord injury, C5 (S14.75)		1		1		2	2	1	2	3	12
Functional spinal cord injury, C6 (S14.76)		1				1		3		2	7
Functional spinal cord injury, C7 (S14.77)										1	1
Injury of thoracic spinal cord unspecified (S24.10)										2	2
Functional spinal cord injury, thoracic level unspecified (S24.70)								1			1
Functional spinal cord injury, T1 (S24.71)								1			1
Functional spinal cord injury, T4/T5 (S24.73)			1					1	1	1	4
Functional spinal cord injury, T6/T7 (S24.74)						1	1				2
Functional spinal cord injury, T8/T9 (S24.75)				1		1		1			3
Functional spinal cord injury, T12 (24.77)								2		1	3
Functional spinal cord injury, Lumbar unspecified (34.70)				1							1
Functional spinal cord injury, Lumbar (34.71)						1					1
Grand total	0	4	1	5	1	16	4	22	5	21	79

Of the total of 79 deaths, 61 patients had cervical level injury (53 males and 8 females), 16 patients had thoracic level injury (13 males and 3 females) and 2 patients had lumbar level injury (2 males).

Table 6.13 shows the data for deaths by age groups and sex.

Table 6-13 Deaths: separation by sex and age range

Age range	16-30	31-45	46-60	61-75	76+	Grand Total
Female	0	1	1	4	5	11
Male	4	5	16	22	21	68
Grand Total	**4**	**6**	**17**	**26**	**26**	**79**

There was a gradual increase in deaths with increasing age in females with the highest number in the 76+ age range. An increase in the number of deaths in males aged 46 and over was noted.

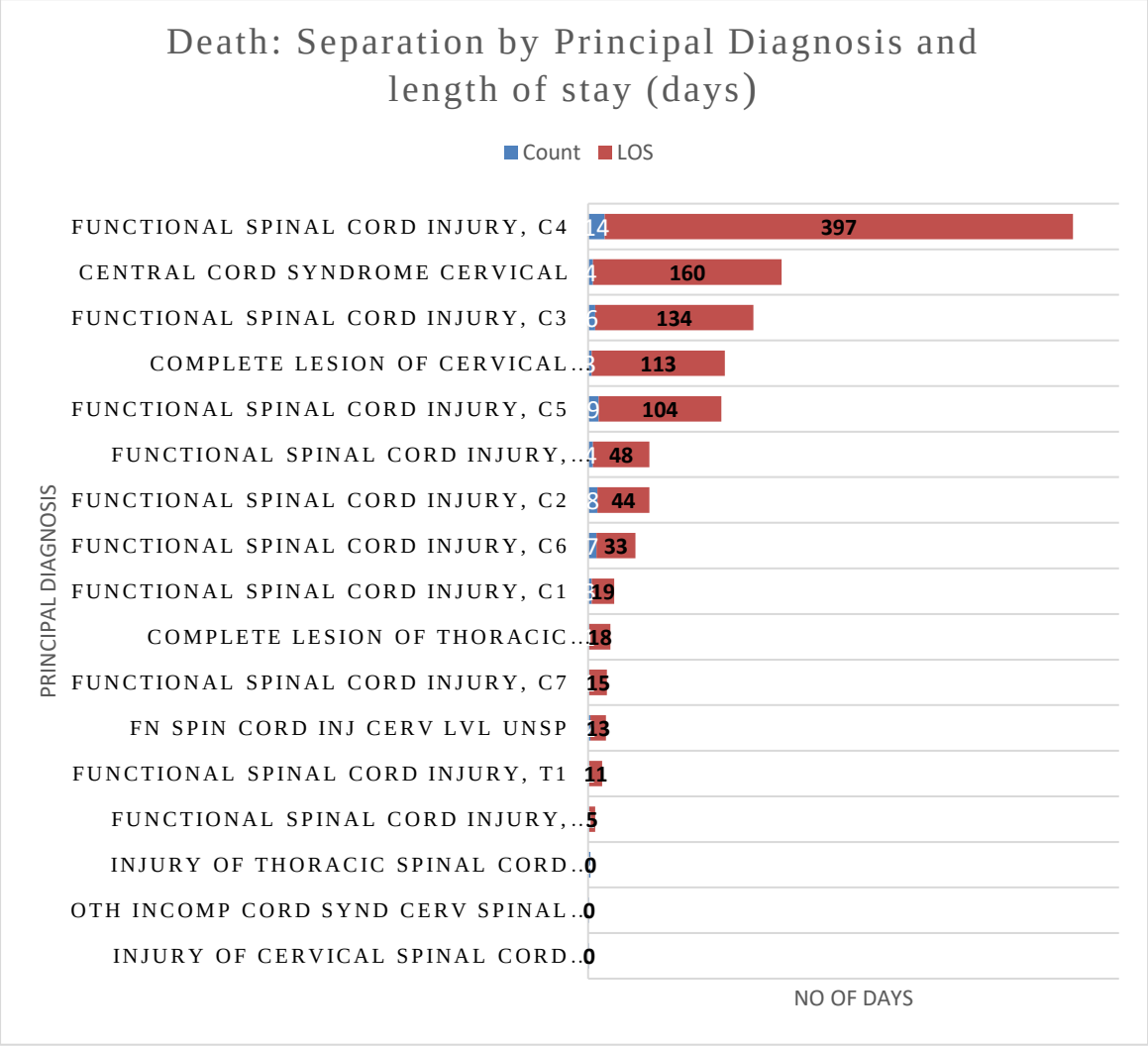


Figure 6-15 Graph of deaths by principal diagnosis and LOS

(See Appendix 6H)

The largest number of deaths in the cohort occurred in those with functional spinal cord injury at C4 (n=14, 20%, 397 days), followed by C5 (n=9, 13.2%, 104 days) and C2 (n=8, 11.8%, 44 days).

Table 6-14 Results of logistic regression investigating the relationship between extended Elixhauser Comorbidity Index, age and LOS (days)

	OR (95% CI)	P value
Elixhauser	1.16 (1.02-1.31)	0.028
Age range		
<=30	reference	
31-45	1.36 (0.34-5.54)	0.664
46-60	7.07 (2.34-21.36)	0.001
61-74	13.22 (4.47-39-12)	<0.001
>=75	29.60 (9.84-89.06)	<0.001
Gender		
F	reference	
M	2.01 (1.03-1.13)	0.041
ICU LOS (days)	1.07 (1.02-1.13)	0.006

OR=odds ratio

Among the deaths recorded, 19 patients had been transferred to Austin Health from the Alfred Hospital and 5 from the RMH as per Figure 6.6.

Patients aged over 45 years were at increased risk of longer LOS (p=0.001). Males had twice the odds of being admitted to Intensive Care Units.

6.5.13 Non-medical ICD-10-AM codes

Many ICD-10-AM codes were not related to medical conditions. These included codes for causes and places of injury, family and medical history, social status, and rehabilitation process, as well as for personal needs such as wheelchair, requirement for carers, and transport dependence. Mostly "U" codes denoted types of injury due to sport, and "Y" for place of accident. All of these non-medical codes were recorded in the same column with medical codes.

The whole cohort of patients with readmissions had a total of 78,205 individual ICD codes. From these a total of 10,810 ICD codes were extracted, which matched principal diagnoses and were separated into medical and non-medical codes. Two thousand five hundred and thirty-four non-medical codes were separated.

Table 6-15 Non-medical ICD-10-AM codes

ICD	Count	Description
U00-U72	57	Sports related injuries
U73.x	391	While working for income, unspecified
U80-V00	16	Unspecified activity
V03-V12	8	Pedestrian injury
V13-22.x	27	Pedal cyclist injury
V23.x-V43.50	40	Motorcycle injury
V43.59-V86.62	54	Car accident injury
V95.9-W01.	4	Unspecified aircraft accident injury
W01-W20.	252	Falls (trees, roof, ladder, building)
W21-W74.	24	Strike, crushed by other objects, or by person
W78-X59	66	Inhalation and exposure to harmful agents,
X61-Y04.09	10	Intentional self-harm & assault
Y85.0	148	Sequelae of motor-vehicle accident
Y86	101	Sequelae of other accidents
Y87.0	18	Sequelae of intentional self-harm
Y88.3	28	Sequelae of surgical and medical procedures
Y92.00-Y92.2	194	Place of accidents: residential institution
Y92.30-Y92.4	26	Place of accidents: Sports and athletics area
Y92.41-Y92.50	229	Place of accidents: street and highway
Y92.7-Y93.9	230	Place of incidence: farm, other unspecified place of occurrence
Z59.0-Z65.3, Z73-Z75.3	102	Other social problems, including care needed
Z72.0	194	Tobacco use, current
Z86.43	253	Personal history of tobacco use disorder
Z86.7-Z92.22	32	Family medical history
Z99.3	22	Dependence on wheelchair
Z94.8-Z99.3	8	Implants and transplants

Causes of injury for TSCI has been extracted and categorized as non-medical codes as shown in Table 6.16 (raw data) and Figure 6.16 below:

Table 6-16 Non-medical codes: Causes of injury

Causes of injury (ICD-10-AM)	Count	Percentage
While working for income (U73.x)	252	41.2%
Falls: tree, roof, ladder, building (W01-W20)	66	26.6%
Inhalation and exposure to harmful agents (W78-X59)	57	7.0%
Sports related injuries (U00-U72)	54	6.0%
Car accident injury (V43.59-V86.62)	40	5.7%
Motorcycle injury (V23.x-V43.50)	27	4.2%
Pedal cyclist injury (V13.-22.x)	24	2.8%
Strike, crushed by other objects, or by person (W21-W74)	16	2.5%
Unspecified aircraft activity (V95.9-W01)	10	1.7%
Intentional self-harm & assault (X61-Y04.09)	8	1.1%

Figure 6.16 shows major causes of injury expressed as percentages.

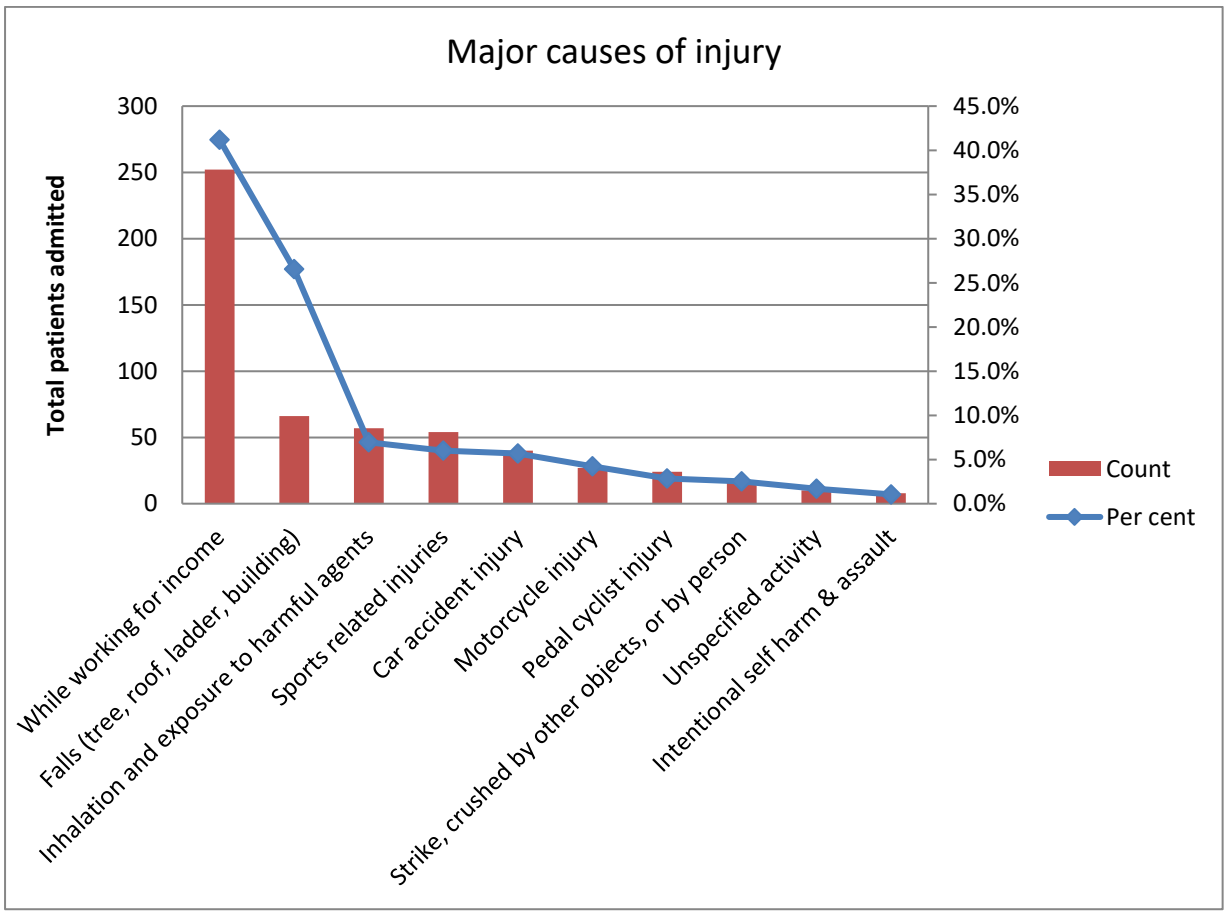


Figure 6-16 Major causes of injury

The highest number of injuries was reported as a result of working for income (41%), and falls (27%); each of the other causes of injury represents less than 7% of total injuries.

The places of injury for TSCI have been extracted and categorized as non-medical codes as shown in Table 6.17 (raw data) & Figure 6.17 below:

Table 6-17 Non medical codes: Place of injury

Place of injury	Count	Percentage
Farm, other unspecified place (Y92.7-Y93.9)	230	33.87%
Street and highway (Y92.41-Y92.50)	229	33.73%
Residential institution (Y92.00-Y92.2)	194	28.57%
Sports and athletics area (Y92.30-Y92.4)	26	3.83%
Total	679	100.00%

Figure 6.17 shows major places of injury expressed in percentage.

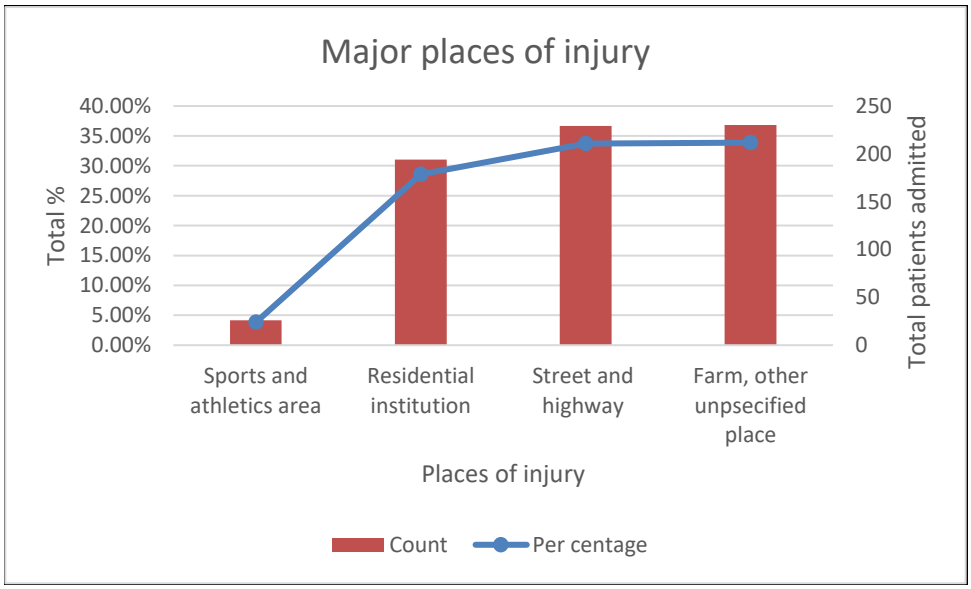


Figure 6-17 Places of injury

The places of injury were categorized as farm, other unspecified place, street and highway, residential institution and sports areas according to ICD codes recorded at the time of admission (Figure 6.17). It is interesting to note that the most frequent place of injury was a farm, other unspecified place (33.9%), followed by street and highway (33.7%), residential address or institution (28.6%) and sports area (3.8%).

6.5 Key Findings from this cohort

- A total of 2,629 patients with traumatic SCI were admitted to three Melbourne hospitals, with a male to female ratio of approximately 3 to 1.
- The largest proportion of male patients with SCI were aged between 16-30 years (27.7%), followed by those aged 31-45 years (22.3%), 46-60 years (19.9%), 61-75 years (17.8%) and 76+ years (12.7%). However, the highest proportion of female admissions for SCI were aged between 16-30 years at the Austin Hospital, 76+ years at the Alfred Hospital and 46-60 years at the Royal Melbourne Hospital.
- There was a notable increase in male admissions from 2003 to 2006 at the Alfred Hospital while there was a consistent rate of 10% of male admissions at the Royal Melbourne Hospital from 2003.
- The analysis of the region where patients resided, expressed as injuries per 100,000, shows that patients from Gippsland had the highest admission, followed by those from the Hume and Grampians regions. Within the Metropolitan areas, the Northern Metropolitan region had the highest number of admissions, followed by the Eastern and Southern Metropolitan areas.
- The most frequent types of traumatic SCI recorded were: functional SCI – unspecified S14.70 (n=333), followed by functional cervical SCI-unspecified S14.11 (n=303) and concussion and oedema of thoracic spinal cord S24.0 (n=202).
- 788 patients out of total 2,629 patients were readmitted; this equates with a rate of readmissions of approximately 30%. From this, 406 patients were readmitted within a month, 290 patients within 3 months, 233 at 12 months and 165 after 2 years post discharge. A significant drop in readmissions was noted after 2 years (93 patients).
- The most frequent reasons for readmission for the cohort over the first eight years were: UTI, pressure ulcer and respiratory complications.
- Health utilization was analysed in terms of length of stay (LOS) at ICU. The highest LOS of 4,045 (S14.70) days was recorded for functional cervical SCI–unspecified. The second highest LOS of 1,640.7 days was for 140 cases with functional lumbar SCI-unspecified (S34.70). The third highest LOS was for 202 patients with concussion and oedema of thoracic SCI (S24.0) with LOS of 1600.8 days.
- An extended Elixhauser Comorbidity Index had a strong correlation with age and gender. Age and being male were risk factors for SCI.

- 3,021 non-medical ICD codes were analysed, showing place, causes and types of injuries. The major causes of injury were work-related, falls and inhalation and exposure to harmful agents. Main places of injury were farms, road accidents and residential homes.
- Analysis of deaths was performed on 79 deaths over the study period. The largest number of deaths occurred in patients with cervical functional injury at C4 followed by C5, with longest length of stay of 397 and 104 days respectively.
- Three deaths were recorded in males in the age range 16-30 years, but no deaths were recorded for females in this age range. An increase in deaths with age was noted in both males and females from the age 46 years onwards. Age (>61 years) and sex (males) are risk factors for this cohort.

6.6 Discussion

The study sought to understand the disease pattern of patients with SCI, its stratification, comorbidities, risk factors associated with SCI and health utilization.

The total number of SCI patients from our cohort over the period mid-2000 mid-2014 after data cleaning was 2,629, comprising 10,810 total episodes. Males were admitted 5.2 times more than females in the age group 16-30 years, decreasing with age, and consistent with the findings of the Austin pilot study and of other studies (New et al., 2015; DeVivo 2012; Cripps, 2006). This study is unique in that it reports age range and sex, whilst most studies show overall male and female admissions only. An increase in major trauma in people above 85 years of age has been reported in a five-year study based in Victoria from 2012 -2016, and this is expected to grow (VSTR, 2017).

The Victorian State Trauma Registry (VSTR) reported stable sex distribution over 5 years from their study (2012-2016), with males accounting for 69-70% of total trauma cases at younger ages and 53-58% over 65 years, not specific to SCI (VSTR, 2017). Our study shows a gradual increase in female admissions at the Alfred Hospital with a peak in 2006, which was maintained after that point. This is in contrast to the data from the Austin pilot study, where there was a slight increase in female admissions in 2002, which was maintained till 2012, and then a gradual increase in 2013. The major trend noted was a significant jump in male admissions from 2003 to 2006 at the Alfred Hospital. This may be explained as being a consequence of the installation of a helipad, which meant that patients were brought directly to the trauma centre rather than being managed in

regional hospitals. The Austin Hospital admissions remained static and many patients were sent to Royal Talbot Rehabilitation Centre for rehabilitation.

The analysis of the region where patients resided, expressed as injuries per 100,000, shows that patients from Gippsland had the highest admissions, followed by those from the Hume and Grampians regions. Within the Metropolitan areas, the Northern Metropolitan region had the highest number of admissions, followed by the Eastern and Southern Metropolitan areas. This finding is consistent with those of the Victorian State Trauma Registry (VSTR) based on all trauma patients (VSTR, 2021). In contrast to the Metropolitan areas, the Austin Hospital pilot study showed the Eastern Metropolitan region to have the highest number of injuries, followed by Northern and South Eastern Metropolitan regions. These differences are probably due to the catchment area of individual hospitals, with the Austin Hospital catchment area being the Northern and Eastern suburbs, the Royal Melbourne Hospital catchment being the Northern and Western suburbs, and the Alfred Hospital catchment, the South Eastern and South Western suburbs.

In the last 20 years there has been a surge in population growth in the Northern metropolitan areas, especially with young families settling there because of affordable housing. We saw a concomitant increase in the number of injuries in this region in the cohort study. A study by the VSTR shows an increase in the percentage of survivors of major trauma discharged directly to home in the period 2016-2017 (VSTR, 2017). Understanding the patterns of place of injury and patients' place of residence will be useful for planning for health services and education.

From this analysis, 51.9% of patients had cervical SCI, 32.6% thoracic SCI, 15.2% lumbar SCI and 0.3% had SCI unspecified. These results are similar to findings reported by National Injuries Surveillance Unit (NISU) in 2009, where half the total traumatic SCI cases were cervical injuries (Henley, 2009).

There was a large percentage of SCI functional unspecified at all three levels: cervical 12.7% (n=333), 3.3% thoracic (n=88) and 3.8% lumbar (n=100). These patients' neurological level would have been classified after discharge by spinal specialists or physiotherapists. It is not possible to identify the correct neurological level of injury from the readmissions. However, in the pilot study (Chapter 5) the neurological level of injury could be traced from sequelae (T91.3). This is the first-time functional SCI unspecified has been included in any study. The publication from the AIHW and Gabbe and Nunn (2016) include functional SCI only. The inability to classify the neurological

level of injury may be related to concurrent conditions preventing a patient's cooperation with the ISNCSCI assessment, for example, inability to follow instructions, or lack of attention, or to immobilization of a limb because of a fracture, where it would be impossible to properly test muscle strength and sensation.

The data on readmissions can provide a rich source of information for clinicians and health policy makers for management of patients with SCI. The top five reasons for readmissions from our cohort were UTI, pressure ulcer, mental disorder, respiratory complications and bowel complications. Our findings are consistent with those of other studies. The incidence of UTI and pressure ulcer has been well documented in many studies (DeJong, Tian, Hsieh, Junn, Karam, Ballard, Smout, Horn, Zanca, & Heinemann, 2013; White & Black, 2016). A study in the USA reported a high percentage of readmissions among people with SCI with the most common conditions being disease of the genitourinary system followed by diseases of the skin and respiratory conditions, whereas pressure ulcer was reported to be a major reason for readmission amongst patients with SCI resulting from gunshot wounds in Southern Michigan (Chopra et al., 2016). Our study extends the findings of a two-year study by Gabbe et al. who reported UTI, pressure area, and bowel complications to be the top 3 reasons for readmission in Australia (Gabbe and Nunn, 2016). Our study confirms UTI and pressure ulcer in the top 10 reasons for ongoing readmissions not just in the first two years post-injury, and provides an indication of the high cost of these complications in people with SCI. This study also shows sleep apnoea as a significant problem as found in a study by Berlowitz (2005). Our study reports mental disorder to be in the top three reasons for readmission which is not reported by Gabbe and Nunn (2016).

The time interval between admissions was also studied, commencing at 1, 3, 6 and 12 months after discharge from the first admission then annually up to 11 years. This study of intervals after injury provides vital information on how well patients recover from major trauma. Adriaansen et al. (2014) studied secondary health conditions associated with SCI, where patients were interviewed by rehabilitation physician after 1- and 5-years post discharge and telephone interview after 2 years (Adriannsen et al., 2013). Their study showed neuropathic pain, musculoskeletal pain and urinary tract infection were the most frequently reported secondary health conditions. Our study does not provide information about pain because patients were not readmitted to hospital to have this problem managed, as it does not appear in the list of the most frequent reasons for readmission. It is interesting that pain (neuropathic, musculoskeletal, or visceral), which is very common after SCI (Siddall and Middleton, 2015), does not appear in the ICD-10AM codes in our patient cohort.

This could be related to a lack of specific reporting, or possibly that it is considered to be well-managed with medication. Our study is the first time comprehensive longitudinal studies of SCI have been conducted providing detailed analysis of complications. Within the first month post-discharge, 51.5% of the cohort were readmitted with one or more of; UTI, pressure ulcer and mental disorder. 54.5 % were readmitted after 3 months, 36.9% after six months, 29.5% after one year and there was a significant reduction to 11.8% after two years. These results highlight the need for ongoing research into better prevention of these complications.

This is the first analysis of studying risk factors associated with SCI. From our study, mental disorder was highest in the young age groups often associated with tobacco, drug and alcohol abuse. The risk factors were inversely proportional to age with the youngest age group having the highest total number of risk factors. Alcohol dependency is shown in the early age groups (16-30 and 31-45). Illicit drugs were used by all age groups but least in the older age groups (76+), and the use of tobacco was more prominent in the younger age group and significantly reduced from the age of 46 onwards. The study highlights that more readmissions occur at younger ages and would lead to higher costs due to longevity and longer periods of medical intervention. A separate study should be considered to find ways to reduce these incidents in young people.

Length of stay (LOS) is associated with cost and resource utilization (Burns et al., 2017), and is used as a measurement of effectiveness and efficiency of treatment. LOS can be a measure of acute LOS, between admission and discharge from the Intensive Care Units (ICU) or between admission to and discharge from the Spinal Units, or between extensive rehabilitation periods (Burns et al., 2017). The only LOS data available were for ICU at Austin Health. From our cohort, the median days of 7.4, 6.4, 4.6 for cervical, thoracic and lumbar respectively. The average LOS for our cohort was median 6.1 days compared to 4 days reported for all trauma patients, including brain damage and SCI (excluding death) (VSTR, 2017). Our results show that LOS is 1.5 times higher than reported by Victorian State Trauma Registry (VSTR), as SCI trauma patients are transferred to Austin Health once they are diagnosed as SCI. Furthermore, the reports from VSTR includes all paediatric cases where our cohort includes adults only (VSTR, 2021). Our study on median LOS in ICU shows published data from VSTR probably under-represents the true picture. LOS is one of important drivers of hospital cost management for traumatic SCI. This study has provided a more detailed estimation of LOS for people with SCI admitted to ICU that has not been previously published in Australia (Burns et al., 2017).

Understanding the place of residence was important for SCI patients as they require continuing medical, social and psychological support after discharge from the trauma centre. The available data included postcodes where patients resided rather than where the accidents had actually occurred. If patients were to return to their original postcode of residence, and given that many are wheelchair-dependent after injury, lack of appropriate transportation may be a major issue and slow health care reform is one of the major barriers in rural regions (Middleton et al., 2008). Our study based on regions showed that Metropolitan region had the highest incidence of SCI (54.5%) of the cohort, followed by Gippsland region (12.1%), Hume (6.8%), Barwon-South Western (6.7%) and Lodden Mallee (5.1%) of Victoria. Whilst metropolitan areas well-serviced under the Victorian health planning, services for patients returning to regional areas are of concern. A study by Middleton et al. (2008) looked at services provided to patients living in rural regions of New South Wales (NSW), where approximately 30% of patients with SCI live. The study found there is a lack of facilities for SCI such as wheel chair access and transportation, lack of health practitioners and lack of specially trained health workers to help the needs of people with SCI (Middleton et al., 2008).

6.7 Limitations

The cohort focused on patients with traumatic SCI, commencing with the first admission, in order to follow the patient journey. However, the study is not able to capture entire readmissions over 14 years as some patients may have been readmitted to other hospitals in between or after readmissions to the three hospitals included here.

Our cohort does not include children and this remains an important gap, as paediatric TSCI accounts for 24 cases per million (Hamid et al., 2018). Given the life span of people with SCI is 40 to 50 years and is expected to grow with the aging population, this can affect the overall planning of health services more than TSCI occurring at a later stage in life.

There are many limitations with data quality in TSCI as multiple custodians are involved. Quality of data requires correct data input and interpretation of various codes, organized in such a way that they can be readily available, managed and stored in a secure location. Currently if a patient moves from one hospital to another, it is not possible to obtain access to the complete patient profile. Data for each patient are kept in different databases within each hospital and it is not straightforward to extract those data in a timely manner.

Risk factors such as use of alcohol, tobacco and illicit drugs were studied to see the impact on the admission and readmissions. Whilst the study showed that age and gender were risk factors, the study was incomplete regarding the effect of tobacco on the respiratory system or effects of illicit drugs on the liver as well as other body systems.

6.8 Future studies

Establishing a patient registry would be a very useful way of capturing all medical care accessed by patients after discharge.

While the Royal Talbot Rehabilitation Centre is part of the Austin Health Network, admission data for this Centre have not been captured in Austin Hospital admissions, which limits follow up studies. Linking datasets with Royal Talbot Rehabilitation Centre would provide deeper insights into the full patient journey, since rehabilitation is an integral part of the management of people with SCI.

The information on sex, age, readmissions and locality can be used for resource allocation, policy planning and intervention after root cause analysis of incidences. Data on re-admissions can provide a rich source of information for clinicians and health administrators for management of patients with SCI. Identifying common causes of readmission should lead to development of better preventative measures for conditions such as pressure ulcers and urinary tract infection (Brinkhof et al., 2016; Guihan et al., 2014).

The information on the region where patients reside provides a foundation for health policy planning regarding provision of ongoing support necessary after discharge, as secondary health conditions are common in the first 5 years post-discharge (Adriaansen et al., 2013). However, to ensure patient journey from first admission, a repository which can store patient information from first admission is necessary.

We have provided detailed stratification of conditions associated with readmissions at different intervals (Appendix 6Da-c; patient journey). Such data can be used to develop an algorithm for prediction for clinical decision support system that can be utilized by clinicians, patients and carers.

Chapter 7

Clinical Decision Support Systems

7 CHAPTER CLINICAL DECISION SUPPORT SYSTEMS (CDSS)

7.1 Introduction

The third guiding question for this research project was concerned with how information gathered from clinical data linkage (CDL) can be used to improve the health of patients through self-efficacy and how this can support clinicians and carers for better management of patient care through Clinical Decision Support Systems (CDSS).

Traditional CDSS comprise software designed directly to match individual characteristics with computerised clinical knowledge to improve clinical decision making (Berner et al., 2007; Garg et al., 2010; Sutton et al., 2020). Such systems use technical devices such as desktops, laptops, tablets and mobile devices to derive medical information from data repositories. However, CDSS today are used at point-of-care, where clinicians combine their knowledge with suggestions made by the CDSS. Well-designed clinical decision support systems have been shown to improve the quality of health care with the application of clinical guidelines (Shaw et al., 2017; Sutton et al., 2020).

The notion of using CDSS has been around for more than 50 years (Kulikowski & Weiss, 1982). The early CDSS were developed in the 1970s, derived from expert systems where developers tried to emulate machines to think like expert clinicians when treating patients (Stowa et al., 2006). From these early studies, there was growing recognition that CDSS could support clinicians with routine tasks by providing various functionalities that would support clinicians to provide accurate diagnoses and minimize human error (Kawamoto et al., 2005; Callen et al., 2006; Georgiou et al., 2008).

However, the adoption of CDSS to their full capacity has not been as substantial as expected. There are barriers to their implementation (Aarts & Koppel, 2009) and challenges to accessing and linking the myriad of information that exists in various data repositories that exist in silos, and these challenges remain to be resolved (Sittig et al., 2008; Shaw, 2017). CDSS have the potential to improve health, with evidence from the domains of geriatrics (Vairaktarakis et al., 2015), laboratory practices (Spyridonos et al., 2002) and radiology (Giordano et al., 2017).

This chapter will provide an historical overview of CDSS and their application and impact in health.

The development of a prototype CDSS specifically for SCI requires a framework, and there are limitations and challenges which are discussed below.

7.2 The evolution of computer intelligence

The development of CDSS in medicine stems from Artificial Intelligence (AI). The aim of classical AI was to model human intelligence in a way that could be emulated and computed by a machine.

Types of AI that are intended to support clinical decisions rely on the manipulation of data and knowledge and are referred to as Expert Systems (Goodman et al., 2012). Expert systems are the commonest type of CDSS in routine clinical use. Research into the use of artificial intelligence in medicine started in the early 1970s and produced a number of experimental systems. In the first decade of research, most systems were developed to help clinicians in the process of diagnosis during an encounter with a patient. Most of these early systems did not develop further than the research laboratory, partly because they did not gain sufficient support from clinicians to permit their routine introduction.

CDSS can be divided broadly into two groups: knowledge based and non-knowledge based. By far the majority of CDSS in medicine are knowledge-based (Berner, 2007). This use compiled clinical knowledge to enable consultation by clinicians. Non-knowledge-based systems use a form of artificial intelligence called machine learning, which operates in a 'trial and error' fashion to find patterns in clinical datasets. This type of learning is similar to human learning (Kabachinski, 2013).

Although there are many different types of CDSS deploying a range of technical functionalities, a typical CDSS includes information on medical conditions, a database that contains patient details (signs, symptoms and laboratory results), and an inference engine to generate case specific advice, as can be seen in Figure 7.1. The inference mechanism contains rule-based systems with specifically defined tasks. There are many variations, but the typical system is represented in the form of a set of rules (Aleksovska-Stojkovska, 2009; Buchanan & Shortliffe, 1984).

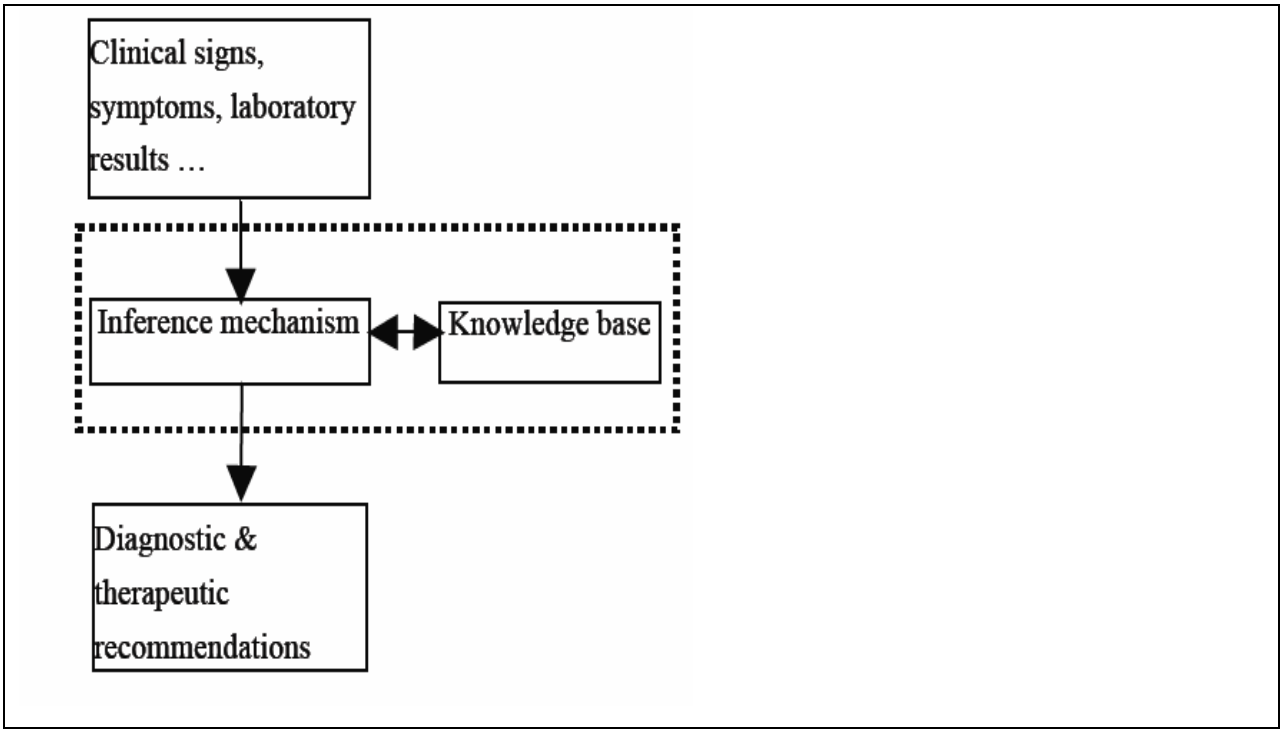


Figure 7-1 General model of expert system (from Aleksovska-Stokjkovska, 2009)

Two types of machine learning are Artificial Neural Networks and genetic algorithms (Negnevitsky, 2002). Artificial Neural Networks (ANN) are widely used in medical information systems and were inspired by theory drawn from the fields of neuroscience, linguistics, computer science, mathematics and physics (Turban, 1995). The aim of ANN is to emulate the biological nature of human adaptive learning, being composed of a large number of processing units that are analogous to human neurons linked together tightly with connection weights (synapses), which resemble human synapses.

The advantages of ANN are the capability to:

- Learn by adapting connection weights to changes in the surrounding environments;
- Deal with imprecise, noisy and problematic information; and
- Generalize from known tasks or examples to unknown ones encountered in the future, mimicking human intelligence (Negnevitsky, 2002).

Broadly, ANN has been used in portal technology, which offers a convenient way of providing information to members of the community through recognition of the user's behaviour patterns (Patridge & Hussain, 1992). The technique has been adopted commercially in e-commerce by using embedded neutral networks to monitor consumer spending patterns (Wang et al., 2021) and credit card delinquencies (Sun & Vasarhalyi 2021).

In the last few decades ANN technology has been applied in many areas in medicine. For example, it has been used in the field of cancer to assist clinical decision-making (Lisboa & Taktak, 2006), as well as to predict functional outcomes one year after discharge from inpatient rehabilitation (Belliveau et al., 2016). Many clinical images can now be automatically interpreted, from plain X-rays through to more complex images such as angiograms, CT and MRI scans. Neural networks are applied in the diagnosis of solid breast nodules (Chen et al., 1999, 2015), and artificial intelligence and pattern recognition are applied in detection of cervical cancer (Bountris et al., 2015), and malaria by CellaVision (Racsa et al., 2015).

CDSS need to fulfil four basic functions (Andrews, 2013; Caplan et al., 2012):

1. Administration: support of clinical coding and documentation, authorization of procedures and referrals.
2. Clinical requirements: keeping patients on research studies and chemotherapy protocols; tracking orders, referrals, follow-up and preventive care.
3. Financial requirements: - controlling costs by avoiding duplicate or unnecessary tests.
4. Decision support - supporting clinical diagnosis and treatment plan processes, promoting best practice, condition-specific guidelines, and population-based management.

7.3 Current application of CDSS in medicine

The application of CDSS has been broad. They have been widely used in nursing (Levett-Jones et al., 2010) and medical education (Barnett, Cimino, Hupp, & Hoffer, 1987). CDSS have been adopted by non-specialists such as community doctors (Farion et al., 2010), as well as by specialists using sophisticated digital methods (Farion et al., 2010). More recently, in the USA, CDSS are used in prescription of menopausal hormone therapy (HT), as well as balancing benefits and risks of using HT for shared decision-making between patients and clinicians (Shufelt and Manson, 2018).

An historical overview of CDSS is presented in chronological order in Table 1. The following section discusses a wide array of CDSS that are applied and in use now, not only in clinical management but in pathology, radiology, and education, as well as in administration and management.

Table 7-1 Taxonomy of CDSS

Name of CDSS	Technology	Description
CASNET/Glaucoma (1960), developed at Rutgers University and implemented in FORTRAN (Fleming et al., 2012)	Expert clinical knowledge was represented in a causal-associational network (CASNET) model for describing disease processes	Diagnosis and treatment for glaucoma
AAPHelp: de Dombal's system for acute abdominal pain (Debono et al., 2013)	A Bayesian approach led to accuracy of 91.8% compared with accuracy of 79.6% by senior clinicians in diagnosing acute abdominal pain.	Diagnosis of acute abdominal pain to identify need for abdominal surgery.
INTERNIST-I (1974) (Miller et al., 1986)	Rule-based expert system – tree structured database that linked diseases with symptoms. Did not use Bayesian or statistical methods, as it tried to emulate how physicians would diagnose patients. First system that dealt with multiple conditions.	Developed to diagnose complex problems in general internal medicine. It used patient observations to identify a list of compatible disease states.
MYCIN (1976), developed by Shortliffe and colleagues at Stanford University (Avillach et al., 2013)	Rule-based expert system using *If-Then* rules; uses domain specific rather than general rules.	Diagnosis of bacteremia by providing consultative advice from data available from microbiology, and clinical chemistry from the directed observations entered by clinicians. Provides explanation of infectious disease therapy and justifies specific recommendations.
PIP (Present Illness Program) (1970), built by MIT and Tufts-New England Medical Centre (Fouad et al., 2013)	Rule-based approach used.	Diagnosis of renal disease from a large set of data. Had ability to generate hypotheses about disease processes.
Dendral	First AI program to emphasize the power of specialized knowledge over generalized problem-solving methods.	Programmed to help chemists elucidate molecular structure.
EMYCIN (1980) [Essential MYCIN], developed at Stanford (Buchanan & Shortliffe, 1984)	Rule-based, domain-independent framework was used; extension of Dendral.	An example of EMYCIN is PUFF (Bottacchi et al., 2012), a system designed to interpret pulmonary function tests for patients with lung disease.
DXplain, developed by Massachusetts General Hospital, Harvard Medical School (Barnett et al., 1987)	Used DSS using database containing 2,200 diagnoses, ranked on probabilities of 5,000 clinical findings.	Educational system: Combines clinical findings including signs, symptoms, laboratory results, to produce a ranked list of diagnoses; also provides differential diagnosis as well as further testing.
ABEL (1980), developed at the Laboratory for Computer Science, MIT, in the early 1980s (Harris et al., 2010).	Expert system using causal reasoning.	Used for the management of electrolyte and acid-base derangements.
ONCOCIN, developed at Stanford University (da Silva et al., 2012)	A rule-based medical expert system. The first DSS which attempted to model decisions and sequencing	Designed to support physicians with the treatment of cancer patients receiving chemotherapy.

	actions over time, using a customized flowchart language.	
QMR (Quick Medical Reference) (Huntington et al., 2012)	Was written in Turbo Pascal, works on any personal computer. DSS with knowledge base containing more than 700 diagnoses and 5,000 clinical findings	Extensive database which provides a quick medical reference to support clinicians.
Prediction of Diabetic Retinopathy (Ogunyemi & Kermah, 2015)	Software using both AdaBoost.M1 (adaptive boosting to combine weighted output) and RUSBoost (class imbalance) techniques.	Prediction of diabetic retinopathy.
Ventilator weaning in ICU (Hsu et al., 2019)	Used two statistical methods: Normalized Compression Distance (NCD) and Multidimensional Scaling (MS).	Used to assist clinical decision-making on appropriate timing of weaning from a ventilator.
Pulmonary Embolism Result Forecast Model (PERFORM) (Banerjee et al., 2019)	A machine learning model using information from the electronic medical record.	Used to forecast Pulmonary Embolism from clinical data.
Antibiotic Stewardship (ABS) Neugebauer & Vogelmann (2020)	Server-based software, accessible via internet browser.	Used to control upper urinary tract infections.

7.3.1 CDSS for acute care

There are many acute care CDSS that have been successfully deployed in medicine:

- HELP (Hospital Information System)

HELP is a data-driven hospital and medical information system. It is a knowledge-based system, written in Practical Extraction and Reporting Language (PERL), invoked by an apache web server linked with a PostgreSQL database. The system supports hospital processes including admission, discharge, and order entry. It has alerts, reminders, data interpretation, diagnostic, and patient management suggestions, and clinical protocols for decision support. The only drawback is that the cases available are limited in number (Haug et al., 1994; Jorm et al., 2012).

- POEMS: Post-operative expert medical system, which interprets clinical data in real time; (Knies et al., 2012). The system is embedded within hospital information systems.
- VIE-PNN: Vienna Expert system for Nutrition of Neonates, a rule-based system for post-natal care decision support (Smailyte et al., 2012).
- NéoGanesh: Closed loop-based knowledge system for ICU ventilator management (Sun, Austin, & Kalra, 2012).

7.3.2 Laboratory information systems (LIS)

One of the areas of medicine that has transformed rapidly in the last two decades has been that of laboratory information systems (King, Baloglu, & Scanlon, 2015). Use of expert systems in the process of automation in pathology has had a huge impact on the efficiency of the work by reducing turnaround times, and reducing human errors (King, Baloglu, & Scanlon, 2015).

Laboratory expert systems usually do not intrude into clinical practice and clinicians do not interact with them. LIS is normally a part of HIS. Within LIS, there can be many small programs such as Remisol (Blick, 2013; Cervinski & Polito, 2011; Hewett & LabPlus, 2010) or IT 3000 (Morling et al., 2012) that sit on the top layer to facilitate work flow and the authorizing process (Zhao et al., 2015). Laboratory staff might have some involvement with setting up the rules criteria, but clinicians do not interact with them. For the pathologist, the system cuts down the workload of generating reports, without removing the need to check and correct them. With computerized order entry, an expert system, some laboratories have a 'virtual lab' where minimum staff are employed. Some examples of LIS are:

- GERMWATCHER: Hospital integration with laboratory analysis of nosocomial infections (Patel et al., 2011; Kahn et al., 1993).
- HEPAXPERT I, II (Adlassnig & Horak, 1991) and III (Chizzali-Bonfadin, Adlassnig, Kreihsl, Hatvan, & Horak, 1997) interpret serology tests for hepatitis A, B, C and D. Hepaxpert III is a knowledge-based system which contains 16 rules for Hepatitis A and 131 rules for Hepatitis B. It is available on the World Wide Web and results can be sent via email. This is an advance on Hepaxpert I which is a stand-alone program with no connection to external databases. Hepaxpert II has a database that can interpret and provide database management and can connect to LIS and HIS. Now Hepaxpert III is available as app to download on mobile phones.

- Pathology Expert Interpretative Reporting System (PEIRS): This rule-based system went into routine use with approximately 200 rules and grew rapidly over a four-year period (1990-1994) to over 2000 rules. It monitors adult drug poisoning. PEIRS interprets about 80-100 reports a day with a diagnostic accuracy of about 95% (Edwards et al., 1993).

7.3.3 Health Educational Systems

- Allergy Expert System (AED): An expert system used for diagnosis and treatment of allergy-related conditions with a personal computer (PC) shell programming environment (Walecki et al., 2006);
- Education for students: An educational model developed to enhance nursing students' ability to identify and manage clinically 'at risk' patients using the 'five rights' of clinical reasoning (Lovett-Jones et al., 2010).

7.4 A conceptual framework for CDSS for management of SCI

The conceptual framework (Evans, 1989; Miles & Huberman, 1994) for a prototype CDSS has been drawn from literature reviews in a range of domains as well as disease trajectories and algorithms from the time series analyses reported in Chapters 5 and 6.

Although the CDSS discussed above are applied in different areas of biomedicine, they all have common themes. Those common to all chronic disease conditions are:

- Primary condition – primary disease, e.g. injury, cancer, diabetes, asthma;
- Intervention – treatment received either at hospitals or prescribed by the general practitioner and to the extent to which the system works to meet patient needs;
- Follow up – follow up treatment or readmission after primary treatment episode;
- Intercurrent illness unrelated to the primary condition;
- Complications – complications from the initial treatment and/or from the follow-up testing, i.e. infection or side effects.

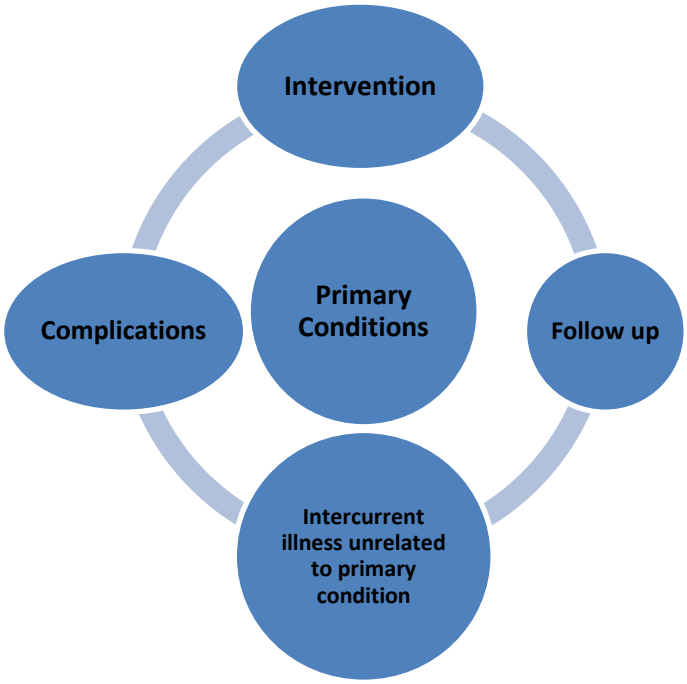


Figure 7-2 Conceptual framework for Chronic Disease

Three 'concurrent flows of activities' comprise the next stage of analysis of these data (Miles & Huberman, 1994, p. 10):

i. Data reduction: the stage that helps to sharpen, sort, focus and organize data in such a way that allows comparisons. The data can be reduced, transformed or subsumed into a larger pattern (Miles & Huberman, 1994, pp. 148-171);

ii. Data display: reduced data are displayed in an organized and compressed way so that a specific case may be compared with other cases. (Miles & Huberman 1994; Yin, 2003);

iii. Conclusion drawing/verification: this is the final stage of analysis, where decisions are made on the basis of patterns that emerge (similarities, differences).

7.5 Development of a prototype CDSS

The rich data obtained from the results of the clinical data linkage reported in Chapters 5 and 6 can form the basis for a prototype CDSS. These historical data provide profiles of a large number of patients with various levels and severity of SCI, together with complications and reasons for readmission. Further development of the CDSS would require ongoing data collection. To develop an effective system, we need:

- Profiling of patients (information from clinical data linkage);
- The ability to predict and prevent complications and adverse events;
- Longitudinal collection of individual and group data sets

7.5.1 Phases in management of SCI

Each patient has time-based longitudinal information, including clinical, functional, psychosocial (family and social support) and vocational information at different phases of the journey after SCI. These include data from:

- Accident Scene
- Retrieval
- Referral
- Admission
- Emergency Management
- Surgery
- Acute Care
- Rehabilitation
- Follow-up at 1 month
- Follow-up at 3 months
- Follow-up at 6-months
- Follow-up 12-months
- Follow-up by community spinal nurses
- Follow-up: annual reviews over next approximately 50 years
- Other outpatient visits
- Readmissions to hospital
- Involvement with other services
- General Practice consultations
- Access to information via web page, which is logged, reviewed and updated

All patients with SCI will have a status in the system related to the above phases, with past and future planned involvement listed, so each health professional is aware of others involved.

Clinical examination and follow up investigations should include:

- List of issues so that an individual profile evolves over time
- Flagging of particular complications or risks
- Easily accessible management strategies
- Consistent information available to support management by health professionals, patient, carer, relative, or community agency
- At each review, recording of current status, recent health issues, complications and efficacy of any prescribed interventions, including medications, for pain, blood pressure control, bladder and bowel management, for example
- Real time recording of contact or failure of planned contact
- Surveillance of patient at risk, with alerts
- Recording of use of clinical resources
- Prediction of risks for better management of both individuals and groups
- Recording of web usage and feedback to evolve process and information system,
- Comparison of time base of events and action and outcome to review and improve process

This will result in a unique long-term database, which ideally contains data on patients' annual follow-up throughout life, whether through metropolitan, rural or interstate clinics.

Software

This application was written in Microsoft Access but could be adapted to run on an Android device if required. The database has been designed to allow queries of expected patient outcomes based on prior history of patients with the same injury and demographic.

Coding to build the dynamic SQL selection

Hard coding of the prototype is shown below:

```
Option Compare Database
Public bRunning As Boolean

Function setQuerySQL() As Boolean
    Dim db As Database
    Dim ws As Workspace
    Dim rs As Recordset
    Dim sSQL As String
    Dim sWhereAnd As String
    Dim sWhereAndSub As String
    Dim sCoMorbidRiskFactor As String
    Dim intCount As Integer
    Dim bFirstRiskFactor As Boolean

    If bRunning Then
        GoTo EndFunction
    End If
    Module1.bRunning = True
    Forms!FormPatientOutcome!txtReadmissions = ""
    Forms!FormPatientOutcome!txtInterval = ""
```

```
    sWhereAnd = " Where"
    sWhereAndSub = ""
    bFirstRiskFactor = True
    sCoMorbidRiskFactor = getCoMorbidRiskFactor()
    sReasons = populateReasons(sCoMorbidRiskFactor)
    sSQL = "SELECT [NumberOfAdmissions], [SumOfInterval], [AveInterval]"
    sSQL = sSQL & " FROM [QuerySelectStats]"
    If dteStartDate > "" Then
      sSQL = sSQL & sWhereAnd & " [QuerySelectStats].[Age Range] = """ &
Forms!FormPatientOutcome!cboAgeRange & """
      sWhereAnd = " And"
    End If
    If Forms!FormPatientOutcome!cboAgeRange > "" Then
      sSQL = sSQL & sWhereAnd & " [QuerySelectStats].[Age Range] = """ &
Forms!FormPatientOutcome!cboAgeRange & """
      sWhereAnd = " And"
    End If
    If Forms!FormPatientOutcome!cboSex > "" Then
      sSQL = sSQL & sWhereAnd & " [QuerySelectStats].[Sex] = """ &
Forms!FormPatientOutcome!cboSex & """
      sWhereAnd = " And"
    End If
    If Forms!FormPatientOutcome!cboPrimaryDiagnosis > "" Then
      sSQL = sSQL & sWhereAnd & " [QuerySelectStats].[PDx] = """ &
Forms!FormPatientOutcome!cboPrimaryDiagnosis & """
      sWhereAnd = " And"
    End If
    If Forms!FormPatientOutcome!cboRegion > "" Then
      sSQL = sSQL & sWhereAnd & " [QuerySelectStats].[Region] = """ &
Forms!FormPatientOutcome!cboRegion & """
      sWhereAnd = " And"
    End If
    If Len(sCoMorbidRiskFactor) > 0 Then
      sSQL = sSQL & sWhereAnd & " [Key(Surname_DOB)] in (" & sCoMorbidRiskFactor & ")"
    End If
    Set ws = DBEngine.Workspaces(0)
    Set db = ws.Databases(0)
    Set rs = db.OpenRecordset(sSQL, dbOpenDynaset)
        While Not rs.EOF
        txtReadmissions = txtReadmissions + rs("NumberOfAdmissions")
        txtInterval = txtInterval + rs("SumOfInterval")
        txtInterval = rs("AveInterval")
        intCount = intCount + 1
        rs.MoveNext
    Wend
    If intCount <> 0 Then
        Forms!FormPatientOutcome!txtReadmissions = Round(txtReadmissions / intCount, 0)
        Forms!FormPatientOutcome!txtInterval = Round(txtInterval / intCount, 0)
    End If
    Forms!FormPatientOutcome!txtPatientCount = intCount
    setQuerySQL = True
    Module1.bRunning = False
EndFunction:
End Function

Function getCoMorbidRiskFactor()
    Dim db As Database
    Dim ws As Workspace
    Dim rs As Recordset
    Dim sSQL As String
    Dim sCoMorbidRiskFactor As String
    Dim sWhereAnd As String
    Dim bFirstRiskFactor As Boolean

    sWhereAnd = " Where"
    bFirstRiskFactor = True
    With Forms!FormPatientOutcome!lstComorbitities
      For i = 0 To .ListCount - 1
        If .Selected(i) Then
```

```
          If bFirstRiskFactor Then
            sSQL = "SELECT [Key(Surname_DOB)]"
            sSQL = sSQL & " FROM [QueryComormidityRiskFactor]"
            bFirstRiskFactor = False
          End If
          sSQL = sSQL & sWhereAnd & " [Comorbidities] = """ & .Column(0, i) & """"
          sWhereAnd = " Or"
        End If
      Next i
    End With
    With Forms!FormPatientOutcome!lstRiskFactors
      For i = 0 To .ListCount - 1
        If .Selected(i) Then
          If bFirstRiskFactor Then
            sSQL = "SELECT [Key(Surname_DOB)]"
            sSQL = sSQL & " FROM [QueryComormidityRiskFactor]"
            bFirstRiskFactor = False
          End If
          sSQL = sSQL & sWhereAnd & " [RiskFactor] = """ & .Column(0, i) & """"
          sSQL = sSQL & "and Ststus = No"
          sWhereAnd = " Or"
        End If
      Next i
    End With
    If Len(sSQL) > 0 Then
        Set ws = DBEngine.Workspaces(0)
        Set db = ws.Databases(0)
        Set rs = db.OpenRecordset(sSQL, dbOpenDynaset)
        While Not rs.EOF
            sCoMorbidRiskFactor = sCoMorbidRiskFactor & """ & rs("[Key(Surname_DOB)]")
& ""","
            rs.MoveNext
        Wend
        getCoMorbidRiskFactor = Left(sCoMorbidRiskFactor, Len(sCoMorbidRiskFactor) - 1)
    End If
End Function

Function populateReasons(sCoMorbidRiskFactor As String)
    Dim db As Database
    Dim ws As Workspace
    Dim rs As Recordset
    Dim sSQL As String
    Dim strItem As String
    Dim sWhereAnd As String
    Dim bFirstRiskFactor As Boolean

    sWhereAnd = " Where"
    bFirstRiskFactor = True
    sSQL = "SELECT Count(QueryReasons.Reason) AS [Count], QueryReasons.Reason, [ICD-
Description].[ascii_short_desc]"
    sSQL = sSQL & " FROM ([QueryReasons]"
    sSQL = sSQL & " INNER JOIN QuerySelectStats"
    sSQL = sSQL & " ON QueryReasons.[Key(Surname_DOB)] =
QuerySelectStats.[Key(Surname_DOB)])"
    sSQL = sSQL & " INNER JOIN [ICD-Description]"
    sSQL = sSQL & " ON QueryReasons.Reason = [ICD-Description].CodeIdFormatted"
    If dteStartDate > "" Then
      sSQL = sSQL & sWhereAnd & " [QuerySelectStats].[Age Range] = """ &
Forms!FormPatientOutcome!cboAgeRange & """
      sWhereAnd = " And"
    End If
    If Forms!FormPatientOutcome!cboAgeRange > "" Then
      sSQL = sSQL & sWhereAnd & " [QuerySelectStats].[Age Range] = """ &
Forms!FormPatientOutcome!cboAgeRange & """
      sWhereAnd = " And"
    End If
    If Forms!FormPatientOutcome!cboSex > "" Then
      sSQL = sSQL & sWhereAnd & " [QuerySelectStats].[Sex] = """ &
Forms!FormPatientOutcome!cboSex & """
```

```
      sWhereAnd = " And"
    End If
    If Forms!FormPatientOutcome!cboPrimaryDiagnosis > "" Then
      sSQL = sSQL & sWhereAnd & " [QuerySelectStats].[PDx] = """ &
Forms!FormPatientOutcome!cboPrimaryDiagnosis & """"
      sWhereAnd = " And"
    End If
    If Forms!FormPatientOutcome!cboRegion > "" Then
      sSQL = sSQL & sWhereAnd & " [QuerySelectStats].[Region] = """ &
Forms!FormPatientOutcome!cboRegion & """"
      sWhereAnd = " And"
    End If
    If Len(sCoMorbidRiskFactor) > 0 Then
      sSQL = sSQL & sWhereAnd & " QueryReasons.[Key(Surname_DOB)] in (" &
sCoMorbidRiskFactor & ")"
    End If
    sSQL = sSQL & " GROUP BY QueryReasons.[Reason], [ICD-Description].ascii_short_desc"
    If Len(sSQL) > 0 Then
        Set ws = DBEngine.Workspaces(0)
        Set db = ws.Databases(0)
        Set rs = db.OpenRecordset(sSQL, dbOpenDynaset)
        For i = Forms!FormPatientOutcome!lstReasons.ListCount - 1 To 0 Step -1
            Forms!FormPatientOutcome!lstReasons.RemoveItem (i)
        Next i
        While Not rs.EOF
            strItem = rs("Count") & ";" & rs("Reason") & ";" & rs("ascii_short_desc")
            Forms!FormPatientOutcome!lstReasons.AddItem Item:=strItem
            rs.MoveNext
        Wend
    End If
End Function


Option Compare Database
Dim bReturn As Boolean

Private Sub cboAgeRange_AfterUpdate()
    bReturn = setQuerySQL()
End Sub

Private Sub cboPrimaryDiagnosis_AfterUpdate()
    bReturn = setQuerySQL()
End Sub

Private Sub cboPrimaryDiagnosis_Change()
    txtPrimaryDiagnosis = cboPrimaryDiagnosis.Column(1)
End Sub

Private Sub cboRegion_AfterUpdate()
    bReturn = setQuerySQL()
End Sub

Private Sub cboSex_AfterUpdate()
    bReturn = setQuerySQL()
End Sub

Private Sub Form_Load()
    cboAgeRange = ""
    cboPrimaryDiagnosis = ""
    txtPrimaryDiagnosis = ""
    cboRegion = ""
    cboSex = ""
    txtPatientCount = ""
    txtReadmissions = ""
    txtInterval = ""
End Sub

Private Sub lstComorbitities_MouseUp(Button As Integer, Shift As Integer, X As Single,
Y As Single)
```

```
    bReturn = setQuerySQL()
End Sub

Private Sub lstRiskFactors_MouseUp(Button As Integer, Shift As Integer, X As Single, Y
As Single)
    bReturn = setQuerySQL()
End Sub
```

Prototype output

The database was constructed by using historical data from the three major Melbourne trauma hospitals. A dynamic query has been constructed and will run each time the user interacts with the screen (Figure 7.3). As the user enters each criterion on the left of the screen, the outcomes will be displayed on the right. So, for example, selecting the age range would find the number of patients in the historic database in that age range and calculation of the average number of readmissions and the average interval between readmissions across those patients. Then, selecting sex would reduce the selected number of patients found and adjust the average values. As more criteria are added, the patient count would reduce further and the averages would be adjusted accordingly.

The application has a single screen which updates the results as data are entered. Figure 7.3 is a screenshot of the user interface.

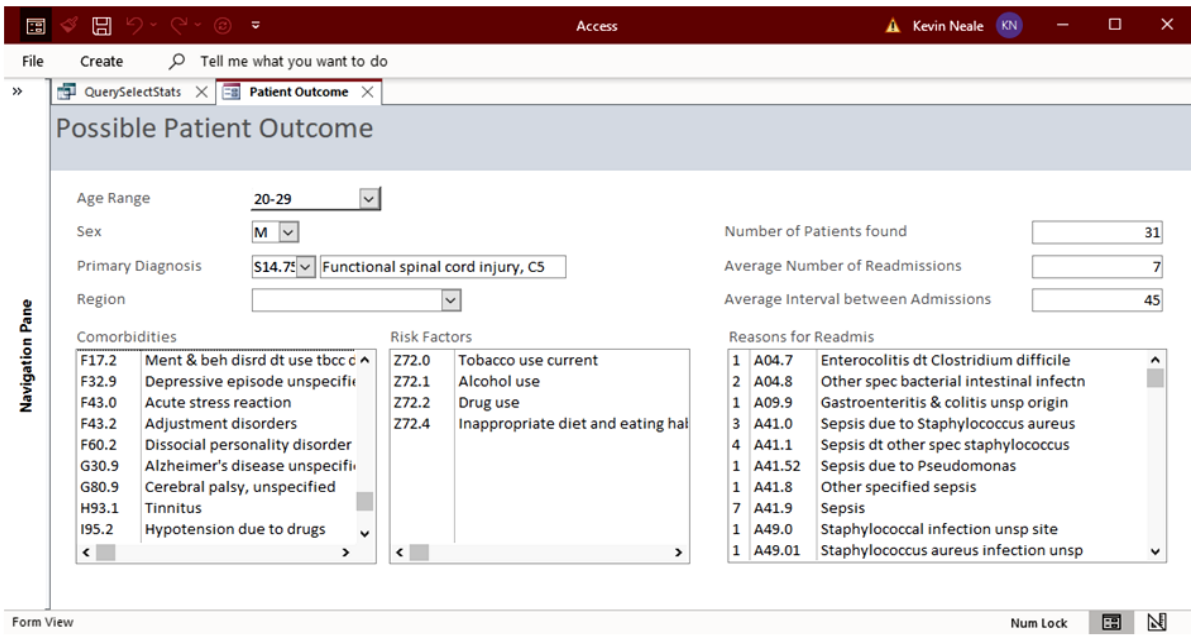


Figure 7-3 Prototype CDSS– Graphic User Interface of Expected Patient Outcome

The prototype provides information about the types of injury associated with age, sex, average readmissions for the specific type of injury, list of reasons for the readmissions, risk factors associated with comorbidities, and the regions where the patients reside.

As can be seen in Figure 7.3, the screen shows a male in the age range 20-29 years, with primary diagnosis of functional spinal cord injury C5 (S14.75). He has been admitted to the hospital seven times with a list of conditions such as infection, with average interval between admissions of 45 days. Comorbidities for this patient are listed as mental and behaviour disturbance, depression, acute stress and adjustment disorder. Four risk factors were tobacco, alcohol, and other drug use and inappropriate diet.

The information can be further refined by continuously:

- providing vital background information from the accident scene through all stages of a person's lifespan;
- providing feedback and support to those managing people with SCI to ensure consistent management with every patient;
- updating individual information continuously with each contact;
- providing an updated management plan individualised for each patient;
- recording any changes in the patient profile

Similarly, information regarding care by external providers can anticipate potential issues and complications to allow prevention and early management:

- Risk management will be facilitated and outcomes reviewed
- Provide protocols, education and information/references. This could be linked to a web interface with more detailed material
- Duplication or lack of consistent accurate information can be monitored and minimized
- Outcomes can be checked and alterations made to the patient profile, plan and data
- With each contact or update, data are collected on the individual and across the service over time, providing a unique research opportunity
- New and rapidly evolving remote sensing technology will facilitate patient monitoring in a functional environment; e.g. it will allow therapy and progress to be managed.

The system will have a built-in management alert system to enable continuous review, so that there will be reminders of investigations. Then, as the size of the cohort increases over time, information about the group will facilitate prediction as clinical issues occur.

Educational Approach

A comprehensive educational approach is needed to further educate clinicians, allied health professionals, GPs and carers by:

- using educational principles to set up a framework on the web page
- reviewing educational effectiveness
- evolving the educational product

Webpage

The webpage enables access to various aspects of the CDSS.

- Data are recorded centrally and users may have different levels of access.

For example, the GP involved would receive a report of the issues at each intervention, ideally electronically. Initially this may be an active word document with backlinks to web-based information pertaining to each issue with different levels of complexity.

On reviewing, the patient with SCI, the GP would have easy and rapid retrieval of pertinent data/information to enable:

- Support information
    - Patient education
    - Basic management protocols
    - Backup evidence-based information for these, including continuing education
    - Appropriate contact links

- Education packages can be customized for an individual from a range of information held in the CDSS, and a shopping cart approach would enable selection of particular relevant information. Thus, many factors, including age, sex, level of injury, education, learning ability and method, interests and discharge situation will determine the best customised package for that person;
- All web contacts would be logged, feedback sought and changes made to support web information
- The web page would provide the desired protocols, education and information as appropriate but also link with other Australian and international sites.

Linking data from Australian and New Zealand Spinal Units and sharing agreed information would be ideal, so that duplication can be avoided and a cooperative and consistent approach nurtured.

7.6 The application of Clinical Decision Support Systems (CDSS)

According to Sintchenko & Garsden (2002), the potential benefits of using CDSS fall into the following categories:

- ***Patient safety***: Improved patient safety by minimizing errors with medications, illegible entries from bad handwriting, misinterpretations and inadequate information.
- ***Continuity of patient care***: Improved quality of care with patient follow-up, providing evidence-based medicine, providing up-to-date clinical documentation that is better coordinated and shared among all treating clinicians and patients.
- ***Healthcare economics***: Improved turnaround time with computerized ordering, reducing duplication and tests through faster processing and minimizing errors using delta checks, thus reducing health costs (Sintchenko & Garsden, 2002; Waegemann, 2002).

7.6.1 Patient Safety

Numerous studies have shown that the use of IT will improve patient safety and care, mostly through a reduction of errors (Buntin et al., 2011; Garg et al., 2010; Kuperman et al., 2006). There is evidence that despite improvements in medicine, there are many patients who die from preventable medical errors in industrialized nations. An alarming report from the US Institute of Medicine indicates that as many as 98,000 people have died of preventable medical errors. Similarly, studies from two London-based hospitals found that 11% of admitted patients experienced adverse events, of which 48% were preventable, and 8% led to death (Kawamoto et al., 2005). It has been reported that as many as one third of errors that are harmful to patients occur while nurses are administering medication to patients (Cloete, 2015). Many levels of error are reported as being due to breakdown in communication; however, a reduction in errors has been reported with the implementation of a sign-out check list (Lam, 2011).

In France, statistics on hospital admissions due to Adverse Drug Reactions (ADR) are significant. In the period 2006-2007, there were 143,915 hospital admissions due to ADR. In one public hospital in the same period, there were 2692 admissions, of which 97 were related to ADR. The study shows that 32% of these were preventable (Bénard-Laribière et al., 2015). The implementation of rule-based computer engines can standardise clinical interventions and mitigate preventable ADR in community hospitals without advanced information technology application

(Seger et al., 2007). The uptake, however, has been slow and there is no study done on errors in people with SCI.

Zaal et al. (2013) reports that the combined use of computerized physician order entry (CPOE) with CDSS has enabled pharmacies to reduce adverse drug reactions, particularly from illegible hand writing that could affect the dosage of medication. A study by clinical pharmacists of the effects of drug related problems (DRP) identified 8% CDSS/CPOE alerts. This is a starting point, as the more sophisticated the programs with pharmaceutical indications and drug reactions are written to the system, the better the performance will be (Zaal et al., 2013).

At first glance, IT solutions seems to be the answer for all, although a retrospective study over the period 2005-2011 in England shows the co-existence of both technical and human errors. However, of the 850 events analyzed, human errors were four times higher than technical errors (Magrabi et al., 2015). Hence there is a need for IT to reduce human errors.

The use of technology has been shown to reduce errors in a specialized area of radiography. The use of information technology in imaging/text analysis has been around since the 1970s, but the uptake has been slow. Computer Aided Detection has become essential in the diagnosis of breast nodules through mammograms (Liu, 2015; Lo, Chang et al., 2015; Sultan et al., 2015). These technologies use a neural network that can be adapted with use and learning from the system (Liu, 2015). However, the question arises: to what extent can diagnosis be made using CDSS? Studies on the correlation between sonography and CDSS were done on solid breast masses using text analysis and neural networks, one form of expert systems. A study done by Chen et al. (1999) showed that out of 140 breast nodules examined, 95% were accurately identified. Since a neural network is a system that is trainable, an improvement in this area is promising (Chen et al., 1999), provided that correct evaluation is done.

7.6.2 Continuity of Patient Care

The benefit of CDSS is hard to measure and there have been very few high-quality studies to show any improvement in patient outcomes (Mollon et al., 2009). Most evaluation has focused on performance in the laboratory setting and this is mainly due to a lack of reliable tools with which to study user behaviour (Sintchenko & Garsden, 2002).

When it comes to patient care, nurses play the major role, as they spend most of their work time with patients and they normally manage the administration of medications. In a study done in a neonatal intensive care unit, a questionnaire was used to evaluate the use of technology on accuracy and **quality**, time, and **health care** information exchange. There was a lot of positive feedback on the use of technology in terms of saving time with writing nursing reports, but it was evident that there were problems with the design of the system (Farshi, Jebreili, & Abdinia, 2015).

In another study, guideline adherence by nurses managing hypoglycemic patients was studied using CDSS built into electronic health records. The initial study showed some promise (25%), although more training was required to get the full benefit of technology (Harrison et al., 2013). Similarly, the impact of using CDSS software in primary care nurse led telephone triage was studies in England. To get the maximum benefit of CDSS, nurses required technical and clinical competencies to be able to capture patient's problems into CDSS (Murdoch et al., 2015).

A limited number of studies have reported the effects of CDSS in a routine clinical setting to see whether the alert system was working adequately and whether relevant patient details were generated for the end-user (Zheng et al., 2005). A randomized trial on the use of the alert systems in hospitalised patients with acute kidney problems showed that the alert systems did not improve patient outcomes (Wilson et al., 2015). However, a comparative study looking at the effects of alert systems in 28 different trials showed an improvement of 5.6% in patient outcome (Shojania et al., 2010).

Two most common reasons for readmissions for SCI are urinary tract infections (UTI) and pressure ulcer (PU). The management of UTI in patients with SCI differs from that of patients without SCI. Often GPs are not aware of this and treat all patients with UTI in the same way (Lin, 2010). GPs normally prescribe antibiotics to treat UTI in patients without SCI. However, patients with SCI who use a catheter must discontinue urinary antiseptics and a urine culture must be taken before re-starting antibiotics (Lin, 2010). There is a strong need to inform treating clinicians and educate young doctors about the correct treatment for patients with SCI.

People with a chronic condition can often benefit from CDSS, as they often need treatments for several conditions at a time which can create complex situations. Polypharmacy is a situation where patients take more than 5 medications on a daily basis. This is highly prevalent among older people with complex health needs and in young populations with several risk factors (Morin et al.,

2018; Halli-Tierney et al., 2019). For example, in a population-based study of all patients aged >65 living in Sweden over the period 2010-2013 (approximately 1.7 million), the prevalence and incidence of polypharmacy was high. On average, an individual was exposed to 4.6 drugs, 44% were taking five or more medications and 11.7% were taking ten or more drugs (Morin et al., 2018). The study claimed that there were many adverse drug reactions as a result of polypharmacy and that there is a lack of systems to initiate "therapeutics intervention", as current treatment guidelines focus on single diseases rather than consolidating multi-morbidity (Halli-Tierney et al., 2019, p34). An algorithm that can match all diagnoses and recommended treatments for a patient's conditions can help identify possible adverse treatment situations. This is only possible if all patient records are shared to avoid prescribing errors, as the prescribers may not be aware of all the medications that are taken by their patients (Lavan et al., 2016). Electronic monitoring of Australian rheumatology patients, for example, had a positive outcome. With the new device, nurses could spend more time on patient care rather than on medication monitoring tasks (Callen et al., 2013).

Many published works on evaluation of CDSS have focused on user satisfaction, and many challenges need to be addressed in structuring such a study. Studies on the effects of CDSS on practitioner performance and patient outcomes have shown that there was a 52% improvement in practitioners' performance but only a 30% improvement in patient outcomes. Overall, few studies have found positive patient outcomes (Jaspers et al., 2011). All of the above studies, however, have led to improvement in the adoption of technology and better design of programs to suit clinical conditions.

Roshanov et al. (2011) conducted a systematic review of the effectiveness of use of CDSS on management of chronic disease. The study found that out of a total of 55 randomized trials, where 87% (n=48) evaluated the impact of the CDSS on the process of care, only 52% (n=25) of cases showed statistically significant improvement in outcomes. Factors such as cost, user satisfaction, system interface and effects on user workflow were not investigated.

7.6.3 Health care and economics

The ultimate motives for using CDSS are to minimize medical error, improve quality of care, reduce duplication of tests and thereby reduce overall health costs. Studies relating to the impact of CDSS have been focused on cost-saving as a result of reduction in medical errors and changes

in management. These studies have limitations in their design and mostly lack an evaluation process. Nonetheless they show promise in many areas of medicine, as described below.

In the hospital setting, intensive care units (ICU) are one of those areas where the cost of health utilization is very high, with one of the highest costs related to the use of ventilators to help patients with breathing. Weaning is the process of gradual reduction in the use of mechanical ventilation. The decision to stop ventilator use can be tricky in that doing so too early would cause undue stress to the patient, whilst delay could cause other problems such as pneumonia or airway trauma. Two statistical methods, Normalized Compression Distance (NCD) and Multidimensional Scaling (MS), used in monitoring CDSS in the weaning process, have been shown to be successful. A study of 380 patients in ICU, showed that weaning with the assistance of a CDSS had a sensitivity of 87.7 %, compared to that of physicians at 61.4%, thus showing a better outcome with the use of CDSS. Hence, with the use of CDSS, the number of days of using ventilator was significantly shortened by 5.2 days, with an overall saving of US$1,500 per patient (Hsu et al., 2013).

Chronic disease management is another area continuously challenging the health budget in most nations. Diabetes is a chronic disease that poses a heavy financial burden on the health system. In the US alone, costs associated with diabetes rose from $174 billion in 2007 to $245 billion in 2013, a rise of 41% (Herman, 2013). The use of CDSS in diabetes management in ambulatory care services has demonstrated an improvement in care and some reduction in cost (14%) (Oxendine et al., 2014).

A study of the use of CDSS on the management of hypercholesterolemia, one of the risk factors for cardiac disease, in 2,221 patients in Spain showed that the use of CDSS did not affect the effectiveness of usual care but led to considerable cost savings (Cobos et al., 2005).

Significant errors in antibiotic prescriptions are reported to have arisen from lack of up-to-date information (Sintchenko et al., 2008). Another study on antibiotics dosage in 1,187 renal patients showed that using CDSS saved up to $116,000 as a result of accurate dispensing and accurate dosing (Helmons et al., 2007).

Clinical decision-making tools have been used to predict length of stay (LOS) in patients receiving rehabilitation following SCI. A discharge date calculator created to predict LOS for patients in rehabilitation using the Functional Independence Measure (FIM) and improved communication was able to effect a 17% reduction in LOS in one fiscal year (Burns et al., 2013).

7.7 Solutions and Recommendations

A CDSS is software that relies on technology. The system requires ongoing education, training and adequate technology. The use of CDSS embedded within either LIS or HIS could replace existing trained staff, thus posing a threat to employment. CDSS can be harmful if the system does not function properly or is not incorporated well into the current clinical system.

For CDSS to be successful, the following areas need to be considered carefully:

- System capabilities
- Software capabilities

7.7.1 System capabilities

The system should have the ability to link to the datasets that currently exist in silos (Sittig et al., 2008) and be able to be coordinated and shared amongst authorized health practitioners. However, this is often hindered by a lack of legible hand writing, organizational structure and non-standardized terminologies (Sintchenko & Coiera, 2003; Sintchenko & Garsden, 2002).

The use of CPOE with CDSS has enabled pharmacies to reduce adverse drug reactions, particularly from illegible handwriting that could affect the dosage of medication (Zaal et al., 2013). At this stage of programming, the system is not yet sophisticated enough to overrule intervention by pharmacists. However, with the development of better programming, fewer staff will be required.

The system could be improved by taking the following steps

- Combining the Electronic Health Record with CDSS to match patient-specific characteristics to a database to assess disease, and to provide appropriate treatments (Shawl et al., 2017)
- Making it easier to use for clinicians who have limited computer experience
- Having an up-to-date medical knowledge-based engine
- Providing correct, culturally sensitive and accurate interpretations
- Justifying interpretations; providing validation rules
- Having easy access from clinicians' work and home
- Learning from users, i.e. evolving and improving as a result of user criticism and analysis of user sessions.

- Maintaining confidentiality and security, installing adequate system backups to protect patient data from being lost, and providing protection from hackers

7.7.2 Software capabilities

Software capabilities that are currently available and can be implemented within Hospital Information Systems (HIS) and Laboratory Information Systems (LIS) with CDSS are:

Quality Control software.

This is used to identify and analyze root causes and thereby minimize medical error. Software such as *Riskman* can be implemented in the system to track sources of error in order to minimize them. *Riskman*, which is used to do 'root cause analysis', was written independently to enhance quality assurance (Lederman et al., 2013; Isaacs, 2021).

Alerts and reminders.

A reminder can be set up in real time to support clinicians and patients in many different areas, such as advice on antibiotics, monitoring of warfarin levels, the control of hypoglycemia in patients with diabetes, and reminders to change the positioning of patients with pressure ulcer. A limited number of studies have reported the effects of CDSS in a routine clinical setting to see whether the alert system was working adequately and whether relevant patient detail was generated for the end-user (Zheng et al., 2005). Overall, few studies have found positive patient outcomes (Jaspers et al., 2011). Moreover, there are mixed reports on the effectiveness of alert systems. A randomized trial on the use of the alert systems with acute kidney patients in hospital showed that the alert systems did not improve patient outcomes (Wilson et al., 2015). However, a systematic review of 28 trials investigating the effects of alert systems showed a median improvement of 5.6% in patient outcome (Shojania et al., 2010). Despite expectations that computer reminders would improve health outcome, this review indicates that any improvement is very small. There is a need for improvement in the system design (Shojania et al., 2010).

Prescribing decision support systems (PDSS).

One of the commonest clinical tasks is the prescription of medications, and PDSS can support by checking for drug-drug interactions, dosage errors, and if connected to an EMR, for contraindications such as allergy. PDSS are usually well received because they support a pre-existing routine task, and as well as improving the quality of the clinical decision, they usually

offer other benefits such as automated script generation and sometimes electronic transmission of the script to a pharmacy (Dramburg, 2020).

Computerized Provider Order Entry (CPOE).

Computer Order Entry together with CDSS has enabled pharmacies to reduce adverse drug reactions, particularly from illegible hand writing that could affect the dosage of medication and minimize duplication of tests, save costs caused by duplications, and avoid unnecessary repetition of tests (Shaw et al., 2017).

System back up and security levels.

A regular backup to protect personal information and to foolproof hardware/software security is essential, as information security in the healthcare sector is a growing concern, particularly in light of the national push for Electronic Health Record (EHR) to be shared among clinicians (Appari & Johnson, 2010). A strategy to protect genetic privacy is recommended (Erlich & Narayanan, 2014).

The system is a written set of rules. Consequently, if there are exceptions or glitches in the system, there is a chance that wrong diagnoses could be made. The system only works if stringent delta checks (algorithm to check results) are done. However, it is impossible to have a perfect solution for all cases presented and impossible to have rules written for all conditions. This can have a significant impact on the delivery and safety of patient care (Castillo & Kelemen, 2013).

7.8 Future research directions

That there has been a rapid adoption of IT in health and consequently increased use of CDSS in medicine is evident. Combined CDSS/CPOE has shown successes in many studies of adverse drug reactions, and with sophisticated programs it has the potential to reduce drug related problems even further (Murdoch et al., 2015).

There are, however, some continuing barriers. Many expert systems are now in routine use in acute care settings, clinical laboratories, and educational institutions, and are incorporated into electronic medical record systems. They are proving to have some success, but the uptake has been slow and the effectiveness of CDSS seems to vary.

Early predictions of pathology laboratories being run by only two scientists have not eventuated, but the virtual laboratory might not be impossible given the speed of development. Though well programmed machines can reduce human errors, they lack the heuristic skills of experienced scientists/clinicians. There needs to be a balance between the automation of pathology laboratories

and human input. There are skeptics, however, in regard to concerns about employment, distrust of software, lack of training and mismatch between user need and supplier.

Information sharing among treating physicians is challenging, as each medical institution has its own record-keeping system, which can cause information loss, misdiagnosis, duplication of tests and repetitive drug prescription (Wu & Wang, 2014). There is a push for a web-based cloud platform that can overcome this problem, though this is still in its infancy (Kaur et al., 2014; Kulkarni et al., 2014).

With sophisticated CDSS systems combined with EHR, there is a capacity to learn, leading to the discovery of new phenomena and the creation of medical knowledge (Castaneda et al., 2015). These machine learning systems can be used to develop:

- Knowledge bases used by expert systems to authorize and scan images for diagnosis and texts to generate reports and interpret results (Castaneda et al., 2015)
- Virtual laboratories with complete re-engineering of laboratories to automation (Kricka et al., 2015)
- Smart Healthcare Platform Construction Based on Cloud Computing that can support remote healthcare, chronic illness management and rural healthcare centres (Zhang et al., 2014)

There is a global push for big data, bringing disparate datasets for EHR to be available and shared among treating clinicians. There is a push for personally controlled electronic health records to be controlled by patients and carers to provide them with autonomy:

> "*Maybe we're not that far away from the home sick bay idea.*
> *Future parent: "Doctor, what's wrong with my child?"*
> *Dr. Hologram: "Nothing at all ma'am, all bio-indicators and CDSS reports indicate a clean bill of health with no current maladies. Send him to school*!"
> (Kabachinski, 2013: p434)

7.9 Conclusion

The advancement of IT in medicine has shown a quantum leap in the last three decades. The historical overview and the application of CDSS in medicine have been discussed above. With computers being ubiquitous, ways to utilize CDSS to increase efficiency, thereby reducing medical error and reducing cost, are showing promise. However, despite technological advancements, the full potential of CDSS has not been explored and much more work needs to be done in the area of evaluation.

Available evidence on the impact of CDSS to deliver improvements in the quality, safety and efficiency of health has been described. Reductions in medication errors and adverse drug events alone appear impressive. To date, the majority of studies have been undertaken in the United States, and importantly, most have involved CDSS systems that have been internally developed and customized for individual health care organizations. The question as to whether the impressive results from such systems will be more widely reproducible is yet to be answered.

In addition, the success of the implementation of CDSS and CPOE will depend on successful IT integration (Aarts & Koppel, 2009) and continued support by senior management. Building a system with increasingly complex decision rules is an arduous task that requires passion, the time of developers, financial support from vendors, and support from collaborating physicians.

With the health budget escalating and with global issues of an aging population and with associated chronic conditions, more emphasis should be put on the use of CDSS for self-efficacy to ensure one's health. This could prove to lead to substantial savings in costs in the long run. One study reported that 74% of organisations which have implemented CDSS stated that their financial viability was a constant struggle. This might be a problem but the expected payoff in health care efficiencies and better outcomes would make it worthwhile (Kabachinski, 2013).

A multidisciplinary service such as an SCI Unit has unique knowledge on overall management, but also specific information about how to manage an individual, which is not always translated consistently or in a usable format to facilitate management by those outside the SCI unit. A CDSS that contains a large amount of data on acute care and rehabilitation plus follow-up at one, three, six and often twelve months, will yield a profile of an individual's medical, physical, emotional, psychosocial and vocational issues that will help guide the provision of the most appropriate management.

Chapter 8

Discussion

8 SUMMARY DISCUSSION, RECOMMENDATIONS AND FUTURE DIRECTIONS

8.1 Introduction

The previous chapters have reviewed the literature on the complexities of spinal cord injury (SCI), its pathophysiology and classification, and the multiple data custodians involved. In addition, the enormous potential of Clinical Data Linkage (CDL) in the medical field was highlighted, especially with respect to long-term medical conditions such as SCI.

SCI patient profiles from two retrospective studies were reported in Chapters 5 and 6. These patient profiles illustrate the SCI patient journey and provide a backbone for eHealth and a possible basis for technology-based clinical decision support systems (CDSS) to better inform patients and treating clinicians. A prototype of a CDSS specific for SCI was developed, with future recommendations that could assist people involved in caring for patients with SCI.

In this concluding chapter, the findings will be summarised, together with recommendations and a possible future direction for the use of administrative health data for clinical data linkage.

8.2 Summary of main findings

To date there has been no CDL for patients with SCI, although other projects involved with data linkage are underway. This thesis reports the first attempt to link data from multiple databases involved with SCI, to assess how an information system via CDL could potentially provide an improved solution for the fragmented health information with respect to this condition in Victoria.

The overall objective of this research was to investigate data about SCI held by multiple stakeholders and the best method of linking the data in order to obtain a full profile of patients with SCI. Without CDL it would not have been possible to understand their health utilisation in the long term. The Austin Hospital pilot study over 10 years provided the opportunity to link datasets within the one institution as well as a basic understanding of the journey of a patient with SCI. Subsequently, a cohort study linking data from three major hospitals over a 14-year period has provided comprehensive information about the types of SCI, places of injury, and importantly, patient readmissions over time.

Although the general high-level findings were similar to those reported by National Injury Surveillance Unit (NISU), which uses health administrative data mainly from the Victorian Admitted Episodes Dataset (VAED) for short timeframes, our data are much richer in that they include information from nine datasets (three internal datasets -VAED, VEDM and ICU- from three major trauma hospitals) over a period of 14 years.

1. In the cohort, we had a total of 2, 629 new SCI admissions, which represented on average 188 patients per year, in Victoria. This is quite high compared to the figure of 264 reported by AIHW (2018) in the period 2014-2015 from the whole of Australia.
2. The main types of traumatic SCI had to be grouped into four: Cervical (51.9 %), Thoracic (32.6%), Lumbar (15.2%) and SCI unspecified (0.3%), as there was inadequate detailed coding from one of the major hospitals to categorize into 44 main principal diagnoses as we had intended. This is consistent with data from the Austin pilot study (Chapter 5), NISU, and reports by VSTR (2017).
3. There were in total 78,208 readmissions in the total cohort, with an average of 30 admissions per patient and 2.1 readmissions per year. The Austin pilot study showed on average 4.5 readmissions per year, higher than for the whole cohort because the Austin Hospital has the specialist spinal cord injury unit, and so a high number of patients with SCI would be expected to return to the Austin Hospital compared to the Alfred or Royal Melbourne Hospitals.
4. Each admission had an average of 25 ICD codes, which equates to 1,955,200 individual ICD codes in total, including medical and non-medical conditions. Whilst the detailed coding of ICD-10-AM can be an advantage, this can also be confusing and can lead to miscoding, and hence affect the overall management of the disease (Hagen, 2009; Najib et al., 2018; Lam 2011).
5. The Austin pilot study provided data on trends in male and female admissions, and the main reasons for readmission. It also identified the patients' areas of residence and costs associated with length of stay. Male admissions increased four-fold over the 10-year study period (1998-2008), compared to a 2.6-fold increase in admissions for women over the same period. Main reasons for readmission were urinary tract infection (UTI), pressure ulcer, fracture and respiratory infections. From the study of frequency of readmission, 34% had only 1 readmission, while 2.2% had more than 11 readmissions. The Eastern Metropolitan area had the highest number of injuries per 100,000 within metropolitan areas, while Gippsland had the highest incidence of injuries in regional areas. Patients with

cervical functional level 5 (C5) had the highest length of stay (LOS), which was the most costly when matched with weighted inlier equivalent separation (WIES) allocation.

6. The major cohort study involving three major hospitals provided much more detailed information about the journey of patients with SCI. The major reasons for readmission for the four main principal diagnoses (cervical, thoracic, lumbar SCI and SCI unspecified) have not been reported elsewhere. The findings were similar in all four groups, with UTI, pressure ulcer, respiratory infection and diabetes among the top ten reasons for readmission. While these were consistent with those reported by other studies (Gabbe and Nunn, 2016), both the pilot and cohort studies revealed a high percentage of mental disorder, especially in the younger age groups. Our study also showed a significant number of patients requiring dialysis, which had not previously been reported, and which may result from bladder dysfunction associated with SCI.
7. The cost associated with SCI was studied in terms of LOS in ICU. The average LOS for the cohort in ICU was 6.6 days, compared to that in the Austin pilot study, which was 3.5 days (Chapter 5), which is similar to the LOS of 4 days reported by VSTR, (VSTR, 2017). The reason for a higher LOS from our cohort could be that patients with more severe injuries were admitted to acute trauma hospitals (Royal Melbourne and Alfred Hospitals).
8. The comorbidities associated with SCI were studied using an extended Elixhauser Comorbidity Index (ECI). The study showed that ECI is directly proportional to LOS and males had a risk of death 2.1 times higher than females.
9. The pattern of readmission and reasons for readmission were followed from the first month post discharge up to the 11^{th} year. The highest number of readmissions occurred within the first 3 months post-discharge (430 patients), and a significant drop in readmissions was noted after two years (93 patients). This does not necessarily mean that readmissions were not required for SCI-related complications. It is possible that patients with SCI may have been admitted to other hospitals in their own locality rather than the major hospitals. The main reasons for readmission were UTI (19%), mental disorder (12%) and pressure ulcer (11%). The individual intervals with reasons for readmission have been captured and presented in Appendix 6.4.9.
10. Risk factors such as alcohol, drug and tobacco use were studied. Alcohol dependency was highest among younger age groups compared to older age groups. Drug use was recorded in all age groups, and use of tobacco was highest in the younger age groups.
11. There were 79 deaths recorded in the Austin pilot study over a period of 10 years. The principal diagnosis of these patients was the cervical functional groups (C4 and C5). They

occurred mostly in males aged 46 and over, and in females the highest number of deaths was in the group aged 76 and over.

12. Major causes of injury and places of injury were studied using extracted non-medical ICD-10-AM codes. The main causes of injury were work-related (41.2%), followed by falls (26.6%) and inhalation of and exposure to harmful agents (7.0%), as well as sports-related injuries (6.0%) The most frequent place of injury was on a farm (33.8%), followed by street and highway (33.7%), residential (28.6%) and sport athletics area (3.8%).

Residency: Most published papers do not discuss the region where patients live, although the place of accidents is discussed. The place of accidents provides the information about the accident; for example, whether traffic-related, work-related or an occupational health and safety issue. Recording the place of residence is important in ensuring provision of continuous support once patients are discharged, as continued support is required by all patients. Traffic accidents that are related to work are reported to the Transport Accident Commission (TAC) as traffic accidents. The TAC is another government body that is separate from the Australian SCI register.

Readmissions: The study provides the first report on the journey of individual patients with SCI over time. Most published papers provide information on readmissions within one- and two-years post-injury (Gabbe and Nunn, 2016) based on total count of comorbidities rather than following individual journeys.

Risk factors: The study provides profiles of patients with risk factors such as use of alcohol, tobacco and illicit drugs, which can be used for future health planning and risk management. Analyses se of risk factors and the extended Elixhauser Comorbidity Index provides insights into the relationship between risk factors, LOS, and death.

Research with health administrative data: The study provides insights into the best practices of Clinical Data Linkage in the world, in English speaking countries. The study identified a range of data custodians and stake holders in the area of SCI, and the challenges of working with health administrative data in Australia. A prototype of a clinical decision support system for patients with SCI has been built to add scalability, together with eHealth, to provide support for both clinicians, patients and carers.

8.3 Issues with health administrative data

Working with health administrative datasets presented many challenges. One source of confusion within the datasets provided for analysis was the difference between a diagnosis of spinal injury and spinal cord injury, as colloquially these terms are used interchangeably. Spinal injury can include fracture or dislocation of the spinal column but not necessarily damage to the spinal cord itself. However, a patient with spinal cord injury may well have had spinal fracture or dislocation but also suffer a serious neurological injury that may require ICU admission. Clearly, the long-term consequences in each case are very different.

The data custodians from the Department of Health and Human Services and health informatics staff from the hospitals involved provided datasets that included patients with spinal injury and those with spinal cord injuries. Therefore, in order to meet our study criteria, the first task was to extract the data on patients with SCI from all datasets.

There are 12,420 medical codes in ICD -10, compared with the previous version, which had 6,969 codes. Whilst the extra codes can be advantageous because of the extra detail, they can be very confusing at the same time. As they stand, health administrative data are unstructured and impossible to make sense of without a huge amount of effort put into context. Each patient episode had, on average, 25 codes at the initial admission, which equates to 65,725 ICD codes (25*2,629 total cohorts). There were 77,208 episodes for the cohort, which equates to 1,955,200 (25*78,208 codes) individual codes (25*14,165).

The disparities in coding for principal diagnosis in the data provided resulted in all the principal diagnoses having to be grouped into four main groups, cervical, thoracic, lumbar and other, to be consistent. However, this kind of miscoding means that the level of detail afforded by the ICD 10-AM is not being used effectively and may lead to inadequate cost management and resource allocation. Furthermore, the clinical utility of the increased number of codes in the ICD-10-AM should be investigated.

Errors in coding found in our study made data linkage unnecessarily complex and time-consuming. Data quality for coding of principal diagnosis was tested in a module of the New South Wales electronic medical record (EMR) (Liaw et al., 2012). The findings suggest that the data in the EMR and its Firstnet module were not accurate or complete enough to be relied on for the various uses of eHealth tools to support safety and quality of care. Our findings and those of the NSW

study highlight a need for a systematic research and development program in data and information quality in health information systems.

Data accuracy has been investigated by Jolley et al. (2015), who looked at the accuracy of coding of "sepsis" in patients admitted to ICU from 1st of January 2009 to 31st of December 2012. The study found that sepsis was under-coded in health administrative data and they suggested that an optimized ICD-coded definition had higher sensitivity and higher validity (Jolley et al., 2015). Our findings were that functional SCI was under-coded in numerous cases.

Another issue with administrative data is that no changes in clinical status (e.g. improvements or decline in function and independence) over time are noted in these data.

8.4 Issues with clinical data linkage

The study involved linking nine databases. Unique identifiers were used to link internal datasets but deterministic methods were used to link datasets from each of three hospitals.
The validation process was designed to address inconsistencies:

- DOB (section 4.8.1) – some patients had DOB but others had age on admission which had to be convert to DOB from other databases in order to create a key which consisted of DOB & surname;
- Surname – Our cohort used keys which concatenated DOB and surname. It's quite possible that surnames can change which could lead to additional record for the same patient. However, this problem can be overcome by sorting by DOB and surname any duplicate DOB for different surnames must then be checked for same person.
- Sex (section 4.8.2) - a male patient was admitted 4 times but was coded three times as a male 3 times and once as a female (Section 4.x);
- Post codes – patients moved from one place of residence to another or at times lived in two different places (section 4.8.3);
- Principal diagnosis (section 4.8.4 & table 4.12) - there were numerous inconsistencies with the principal diagnosis especially when the patient was discharged with functional unspecific codes, especially those who were not completely well enough to be accurately assessed using the ISNCSCI and therefore could not have the level and severity of injury accurately determined (Table 4.12)
- Coding of ICU datasets (coded as per ANZIC-APD) had to be converted to ICD-10-AM, which required internal data linkage of unique identifiers to extract principal diagnosis.

In general, this was possible if the patients were readmitted however, for those who were not readmitted, the ICU datasets were coded manually from ANZIC-APD to ICD-10-AM from the description.

The clinical data linkage of the three hospitals required deterministic methods involving concatenating name with DOB, sex, principal diagnosis and post code. A problem that can occur with this method is that there could be several patients with same name born on the same day. Fortunately, that did not happen with our datasets but if that were the case, concatenating name with sex, principal diagnosis and post code could eliminate duplication. It should be borne in mind that both sex and post codes are dynamic; sex change is rare, but post codes can change readily as people move place of residence, and this could create multiple records for the same person.

There were many instances of inconsistencies in the principal diagnosis especially when patients were transferred from one hospital to another. This is partly due to the inability to assess a patient accurately at the initial discharge as the assessment requires patients to be well, however, often patients are not completely well when they are discharged from the first hospital. Readmissions assume the patients are returning to the same hospital. However, if they live far away from the hospital, it might not be possible for them to return to the same hospital. It is possible that some patients might have attended local hospitals especially if they lived in regional areas and only return to the major trauma hospitals for serious conditions that require special equipment or involve seeing a specialist. Hence, capturing all readmissions is difficult and there could be a gap in tracking all conditions of any one patient.

8.5 Recommendations for future directions

A number of recommendations can be made on the basis of the studies reported in this thesis:

1. The multiple datasets for SCI should be linked to avoid repetition and duplication.
2. Clinical data linkage processes should be streamlined to facilitate future studies and make data more readily accessible to researchers.
3. Professional development workshops should be made available to all staff involved in the coding of health administrative data to ensure conformity within and across hospitals.
4. Coding of health administrative data should have a validation system to ensure medical conditions are entered correctly in the order expected. This is necessary for data linkage algorithms to be effective.
5. Currently the ANZICS–APD database is independent. This should be linked with VAED

so that information essential for managing critical care unit patients is shared.

6. Further development of a CDSS from the prototype discussed in Chapter 7 would make it possible to assist clinicians in coordinating and consolidating medical treatments, and en able self-efficacy for patients and carers.

8.6 Limitations

There are several limitations to note with this work. First, it was based on a retrospective analysis of existing datasets of people with traumatic SCI, datasets which were not primarily collected for research purposes. As such, we were limited to the variables contained in those datasets.

Secondly, our study was limited to adults (those aged 16 years and older), and therefore it does not capture paediatric injuries. Nor did it include patients with non-traumatic SCI. This may affect the generalizability of our results. Furthermore, the number of females admitted to ICU was too low to conduct any statistically meaningful analyses of trends over time.

Thirdly, our study of readmissions does not capture all patients with traumatic SCI, as not all of them returned to the hospitals where they were first treated. Many would have been admitted to local hospitals where records are kept separately.

8.7 Conclusion

This is the first Australian longitudinal retrospective data linkage study of patients with SCI, over a 14-year period, showing the trends of disease as well as health service utilization. The study involved linking ICU datasets with VEMD and VAED to work out determinants for disability, as well as the main reasons for readmissions. The issues involved with clinical data linkage using health administrative datasets have been discussed and recommendations for quality and accuracy of data have been made. These will be crucial for developing e-health. Correct coding would ensure that the detail afforded by the ICD-10 is utilized effectively to add to the value of data linkage.

The comprehensive patient disease profile developed in this study can be used as a backbone for CDSS to provide guidance to clinicians, patients, carers and health administrators with pathophysiology, education, resource planning and health policy. The richness of the data, which provides different information from that of the trauma registries, is important for clinicians in enabling them to obtain a deeper understanding of the sequelae of SCI.

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10 Appendices

10 APPENDICES

Ethics approvals (Appendices A-E)

This research required ethics approval from four different institutions: The University of Melbourne, Austin Health (2 approvals: one for the Austin Pilot Study and one for the cohort to include RMH), Alfred Health and Royal Melbourne Health: (Appendices 1A - 1E).

Appendix A: Ethics approval from the University of Melbourne

THE UNIVERSITY OF MELBOURNE
HUMAN RESEARCH ETHICS COMMITTEE

APPLICATION FOR APPROVAL OF RESEARCH INVOLVING HUMAN PARTICIPANTS

THE UNIVERSITY O
MELBOURNE

A. ADMINISTRATION DETAILS

APPLICATION TYPE:	Registration	**ETHICS ID:**	1237523
RESPONSIBLE HEAG:	Engineering	**HESC:**	Behavioural and Social Sciences
ADMINISTERING DEPARTMENT:	510 - Melbourne Medical School	**ADMINISTERING CENTRE:** (if applicable)	

B. PROJECT DETAILS

Title: Long term clinical outcome of acute spinal cord injury: Time series analysis using retrospective administrative and clinical data.

Project Type: Supervised Student Research Project - PhD

Research Involves: Already has or requires other ethics approvals
Involvement of health, personal or sensitive information without consent

Brief Description: Most patients with acute SCI need extensive treatment and need continuous medical services requiring follow-up sessions with clinicians and/or allied health professionals.
Once, they are discharged from hospitals they then go under extensive treatment at the rehabilitation centres and visits to General Practioners are frequent. They often have frequent re-admissions to hospitals as results of a range of secondary conditions associated with SCI.

However, patient} information is not always available for reference in follow-up care. This is a particular concern for patients in rural and outside of metropolitan areas. Little is known about the frequency of re-admissions and resource utilization by SCI patients over time either in or outside of metropolitan areas.

This study seeks to use medical records to generate a patient profiles for long term complications of Spinal Cord Injury (SCI). It is hoped that by generating patient risk profiles, preventive treatments and education programs based on this information can be implemented for patients, families and health care practitioners to reduce the morbidity and cost of SCI.

From the patient profile, it is hoped to develop a model of an effective clinical decision support system to predict Clinical/education intervention in prevention of predictable complications of SCI. The information would allow us to have better understanding of epidemiology of SCI patient}s on clinical, social and econometric measures.

Proposed Duration of whole Research Project: **From:** FEB-2012 **To:** APR-2014

Proposed Date to Commence Data Collection: 01-MAR-12

Appendix B: Ethics approval from Austin Health

Austin Health

Austin Hospital

145 Studley Road
PO Box 5555 Heidelberg
Victoria Australia 3084
Telephone 03 9496 5000
Facsimile 03 9458 4779
www.austin.org.au

Date: 14 January 2015

To: **Ms Jane Moon**
Pathology Department, Austin Health
A/Prof Graeme Hart
Intensive Care Unit, Austin Health

Project: **Long term clinical outcome of acute spinal cord injury: Time series analysis using retrospective administrative and clinical data**

HREC Ref No: **H2011/04539**

Amendment Approval
Protocol updated to include 3 different patient databases and extend the years of research from 1998-2008 to 1998-2014

Thank you for submitting your amendment detailed above I can confirm that the submission was received on the 21st of December 2014. I wish to inform you that out of session approval has been granted for this Amendment.

It should be noted that all requirements of the original approval still apply.

Yours sincerely,

Dr Sianna Panagiotopoulos, PhD
Manager, Office for Research

This HREC is constituted and operates in accordance with the National Health and Medical Research Council's (NHMRC) *National Statement on Ethical Conduct in Human Research (2007), NHMRC and Universities Australia Australian Code for the Responsible Conduct of Research (2007) and the CPMP/ICH Note for Guidance on Good Clinical Practice annotated with TGA comments (July 2008) and the applicable laws and regulations; and the Health Privacy Principles in The Health Record Act 2001.* The process this HREC uses to review multi-centre research proposals has been certified by the NHMRC.

Appendix C: Memorandum of Understanding required to include Royal Melbourne Hospital

Austin Hospital

145 Studley Road
PO Box 5555 Heidelberg
Victoria Australia 3084
Telephone 03 9496 5000
Facsimile 03 9458 4779
www.austin.org.au

This **Memorandum of Understanding** is dated the last date on which it is executed.

BETWEEN:

AUSTIN HEALTH (ABN 96 237 388 063) of 145 Studley Road, Heidelberg, Victoria 3084 **AUSTRALIA (*AH*)**

AND the party or parties (*Collaborator*) named in Item 2 of Schedule 1.

RECITAL

The parties wish to conduct research and development with a view to achieving agreed research objectives through a research or quality improvement project, the "Research Project," as specified in Item 1 of Schedule 1, on the terms and conditions set out in this Memorandum of Understanding.

IT IS AGREED AS FOLLOWS:

1. RESEARCH PROJECT

Each party agrees to carry out its obligations in accordance with the *National Statement on Ethical Conduct in Human Research 2007 and The Australian Code for the Responsible Conduct of Research 2007 (*as varied or replaced by the National Health & Medical Research Council, the Australian Research Council and Universities Australia).

1.1 Each party must:

(a) bear its own costs under this Memorandum of Understanding; and

(b) obtain and comply with all required authorisations from government agencies and ethics committees which are required for the Research Project unless one party is nominated at Item 4 of Schedule 1; and

(c) not knowingly infringe, and use its best endeavours not to infringe, the Intellectual Property rights of any person in carrying out the Research Project; and

(d) carry out the Research Project in accordance with all applicable laws.

2. PROJECT INTELLECTUAL PROPERTY (IP)

2.1 Except for copyright in a student thesis (see clause 2.22.2) Project IP will be jointly owned by the parties as tenants in common in the proportion set out in Item 5 of Schedule 1 and no party may:

(a) grant a licence of its share of any Project IP; or

(b) assign its share of the Project IP,

without the written consent of all parties, which shall not be unreasonably withheld.

2.2 The parties agree that copyright in a student thesis will be owned by the student but the party responsible for the student will ensure that the student enters into a written agreement, which is consistent with this Memorandum of Understanding, before the student commences any Research Project activities.

2.3 The parties will notify each other of any Project IP that might have commercial potential and the parties will negotiate in good faith the terms of any Commercialisation of the Project IP so as to share fairly any associated commercial return.

2.4 The parties are committed to appropriate recognition of contributions to invention and exploitation of Intellectual property for the benefit of the Australian community.

3. BACKGROUND IP

3.1 Each party warrants that it either owns, or is properly licensed to use, its Background IP and that it has the right to grant the licence in clause 3.2.

3.2 Each party grants to the other party for the Term a royalty free, non-exclusive licence to use that party's Background IP for the purposes of this Memorandum of Understanding only.

3.3 Subject to clause 3.2, no provision of this Memorandum of Understanding affects the rights inherent in the Background IP.

4. PUBLICATION

4.1 At least 28 days prior to any publication, the publishing party will provide a copy of the proposed publication to each other party.

4.2 The other parties may provide comments and/or reasonable amendments to the publication to protect their Confidential Information and/or Intellectual Property provided they are given to the publishing party in writing no later than 14 days before the publication is proposed. If no such comments or amendments are provided within those 14 days the publishing party can publish.

4.3 All publications will recognise the contribution by the parties to the Research Project.

4.4 The parties are committed to appropriate recognition of contributions to invention and exploitation of Intellectual property for the benefit of the Australian community.

5. INSURANCE

5.1 Each party shall effect and maintain adequate insurance to cover its conduct in the Research Project.

6. GENERAL

6.1 This Agreement constitutes the entire agreement and understanding between the parties with respect to the subject matter of this Agreement.

6.2 This Agreement is governed by the laws of the State of Victoria and each Party submits to the exclusive jurisdiction of the courts of that State.

EXECUTED as an agreement by the parties on the last date hereinafter appearing

AUSTIN HEALTH **Principal Investigator**	**COLLABORATOR** **Principal Investigator**
Jane Moon 3rd Nov, 2014	**A/Prof. Nerida Harley, 3rd Nov, 2014**
SIGNATURE AND DATE	SIGNATURE AND DATE
NAME [please print] PhD Candidature, Medical Scientist Austin	NAME [please print] NERINA HARLEY
[*POSITION TITLE*]	Director of ICU [POSITION TITLE]

Appendix D: Site specific assessment authorization from Royal Melbourne Hospital

PO Royal Melbourne Hospital
Parkville Victoria 3050
Telephone 61 3 9342 8530
Facsimile 61 3 9342 8548
Email: research@mh.org.au
Website: http://research.mh.org.au
ABN 73 802 706 972

OFFICE FOR RESEARCH

MELBOURNE HEALTH

SITE SPECIFIC ASSESSMENT (SSA) AUTHORISATION

APPROVAL TO CONDUCT A RESEARCH PROJECT AT MELBOURNE HEALTH

Ms Jane Moon
University of Melbourne
University of Melbourne Royal Park Campus
34-54 Popular Road,
3052
Australia

6th July 2015

Dear Ms Moon

HREC Reference Number: HREC/15/MH/229

Local Project Number: 2015.169

Study Title: Long term clinical outcome of acute spinal cord injury: Time series analysis using retrospective administrative and clinical data

SSA Reference No: SSA/15/MH/237

SSA Authorisation Date: 6th July 2015

Reviewing HREC: Austin Health Human Research Ethics Committee (EC00204)

HREC Approval Date: 10th November 2014

I am pleased to advise that the above project is approved to be conducted at Melbourne Health. This approval is subject to compliance with any conditions imposed by the reviewing HREC.

SSA Approved Documents:

- Austin Health HREC Approval Letter dated 10th November 2014
- Research Proposal Protocol number, version and date].

Research governance

You are required to notify the Office for Research of:

1. The actual start date of the project at Melbourne Health.
2. Any amendments to the project after these have been approved by the reviewing HREC
3. Any adverse events involving patients of Melbourne Health, in accordance with the Melbourne Health Guidelines for Monitoring and Reporting of Safety in Clinical Trials Involving Therapeutic Products and Other Clinical Research, July 2009.
4. Any unforseen events.

5. Any changes to the indemnity, insurance arrangements or Clinical Trial Research Agreement for this project. This includes changes to the project budget or other changes which may have financial or other resource implications for Melbourne Health.
6. Your inability to continue as Principal Investigator or any other change in research personnel involved in the project.
7. Any other matters which may impact the conduct of the project at Melbourne Health.

You are also required to submit to the Office for Research:

8. A copy of the TGA acknowledgement letter in respect of the CTN notification (if applicable).
9. An Annual Progress Report every 12 months (or more frequently as requested by the reviewing HREC) for the duration of the project. This report is due on the anniversary of HREC approval. Continued SSA and HREC approval are contingent on receipt of an annual report by the reviewing HREC and the Research Governance Office.
10. A comprehensive Final Report upon completion of the project.

Melbourne Health requires that every participant enrolled in a research project be registered on the iPM patient database as a research participant at the time they are first enrolled or consented. This must be done in real time in order to ensure patients safety. For further information please refer to the Office for Research website iPM page at http://www.mh.org.au/research-participation-in-ipm/w1/i1018219/.

The Office for Research may conduct an audit of the project at any time.

Please refer to the Office for Research website to access forms such as the Amendment Form, Annual Report/Final Report Form, Guidelines for Monitoring and Reporting of Safety in Clinical Trials Guidelines and Adverse Event Report Forms, and other information and news concerning research at Melbourne Health:
http://www.mh.org.au/www/342/1001127/displayarticle/1001352.html

Please Note: Template forms for reporting Amendments, Adverse Events, Annual Report/Final Reports, etc. can be accessed from: www.health.vic.gov.au/cchre.

Yours sincerely,

Dr Angela Watt
Director Research Governance and Ethics

Appendix E: Ethics approval from Alfred Health

TheAlfred

ETHICS COMMITTEE CERTIFICATE OF APPROVAL

This is to certify that

Project No: 566/15

Project Title: Long term clinical outcome of acute spinal cord injury: Time series analysis using retrospective administrative and clinical data

Principal Researcher: A/Professor David Pilcher

was considered for Low Risk Review and APPROVED on **18/12/2015**

It is the Principal Researcher's responsibility to ensure that all researchers associated with this project are aware of the conditions of approval and which documents have been approved.

The Principal Researcher is required to notify the Secretary of the Ethics Committee, via amendment or report, of

- Any significant change to the project and the reason for that change, including an indication of ethical implications (if any);
- Serious adverse effects on participants and the action taken to address those effects;
- Any other unforeseen events or unexpected developments that merit notification;
- The inability of the Principal Researcher to continue in that role, or any other change in research personnel involved in the project;
- A delay of more than 12 months in the commencement of the project; and,
- Termination or closure of the project.

Additionally, the Principal Researcher is required to submit

- A Final Report on completion of the project.

Approval covers the project as described in the application (including any modifications made prior to approval). Low Risk projects are subject to audit and ethical approval may be withdrawn if the project deviates from that proposed and approved.

SPECIAL CONDITIONS

None

SIGNED:

Professor John J. McNeil
Chair, Ethics Committee

Please quote project number and title in all correspondence

Appendix 4: Methods (Appendices 4A-4F)

Appendix 4A: Separation by Regional Areas

A master file with complete post codes in Victoria was created in addition to Victorian electorates to separate into regions all the patients admitted to the three hospitals.

There were in total 3,895 rows. Below is a sample of each region.

Locality Name	Post Code	Municipality Name	Region Name
Chatsworth	3379	Ararat Rural City Council	Grampians
Bung Bong	3465	Central Goldfields Shire Council	Loddon Mallee
Little River	3211	Greater Geelong City Council	Barwon-South Western
Goulburn Weir	3068	Greater Shepperton City Council	Hume
Tinamba	3859	Wellington Shire Council	Gippsland
Footscray	3011	Maribyrnong City Council	Western Metropolitan
Melbourne	3004	Port Phillip City Council	Southern Metropolitan
Fawkner	3060	Hume City Council	Northern Metropolitan
Eaglemont	3084	Banyule City Council	Eastern Metropolitan
Rowville	3178	Knox City Council	South Eastern Metropolitan

Appendix 4B: Locality post codes

There are 74 pages of Victorian Electorates by locality and postcode, which has been used to separate patients living in metropolitan areas. A sample of the first page is shown below.

Victorian Electorates by Locality and Postcode

Count of Electors and Properties (households) for State Enrolled Electors ONLY as at 28 Jan 2016

Locality Name	Post Code	Municipality Name	Ward Name	LGA	District Name	District Code	Region Name
Abbeyard	3737	Alpine Shire Council	Unsubdivided	52201	Ovens Valley	65	Northern Victoria
Abbotsford	3067	Yarra City Council	Langridge	51301	Richmond	70	Northern Metropolitan
Aberfeldie	3040	Moonee Valley City Council	Buckley	55601	Niddrie	62	Western Metropolitan
Aberfeldy	3825	Baw Baw Shire Council	North	53503	Narracan	58	Eastern Victoria
Acheron	3714	Murrindindi Shire Council	Eildon	53003	Eildon	24	Northern Victoria
Acheron	3714	Murrindindi Shire Council	Koriella	53006	Eildon	24	Northern Victoria
Adams Estate	3984	Bass Coast Shire Council	Leadbeater	53404	Bass	3	Eastern Victoria
Addington	3352	Ballarat City Council	North	50302	Ripon	72	Western Victoria
Adelaide Lead	3465	Central Goldfields Shire Council	Paddys Ranges	56303	Ripon	72	Western Victoria
Agnes	3962	South Gippsland Shire Council	Coastal-Promontory	53801	Gippsland South	36	Eastern Victoria
Aireys Inlet	3231	Surf Coast Shire Council	Anglesea	50101	Polwarth	67	Western Victoria
Airly	3851	Wellington Shire Council	Unsubdivided	53901	Gippsland East	35	Eastern Victoria
Airport West	3042	Moonee Valley City Council	Rose Hill	55603	Niddrie	62	Western Metropolitan
Albanvale	3021	Brimbank City Council	Grasslands	54201	Kororoit	42	Western Metropolitan
Albert Park	3206	Port Phillip City Council	Albert Park	51101	Albert Park	1	Southern Metropolitan
Albert Park	3206	Port Phillip City Council	Emerald Hill	51104	Albert Park	1	Southern Metropolitan
Alberton	3971	Wellington Shire Council	Unsubdivided	53901	Gippsland South	36	Eastern Victoria
Alberton West	3971	Wellington Shire Council	Unsubdivided	53901	Gippsland South	36	Eastern Victoria
Albion	3020	Brimbank City Council	Harvester	54202	St Albans	78	Western Metropolitan
Alexandra	3714	Murrindindi Shire Council	Koriella	53006	Eildon	24	Northern Victoria
Alexandra	3714	Murrindindi Shire Council	Red Gate	53007	Eildon	24	Northern Victoria
Alfredton	3350	Ballarat City Council	Central	50301	Wendouree	84	Western Victoria
Alfredton	3350	Ballarat City Council	North	50302	Wendouree	84	Western Victoria
Alfredton	3350	Ballarat City Council	South	50303	Wendouree	84	Western Victoria
Allambee	3823	Baw Baw Shire Council	Mount Worth	53502	Narracan	58	Eastern Victoria
Allambee Reserve	3871	Baw Baw Shire Council	Mount Worth	53502	Narracan	58	Eastern Victoria
Allambee Reserve	3871	South Gippsland Shire Council	Tarwin Valley	53803	Gippsland South	36	Eastern Victoria
Allambee South	3871	South Gippsland Shire Council	Tarwin Valley	53803	Gippsland South	36	Eastern Victoria
Allans Flat	3691	Indigo Shire Council	Unsubdivided	52601	Benambra	6	Northern Victoria
Allansford	3277	Moyne Shire Council	Unsubdivided	51801	South-West Coast	77	Western Victoria
Allansford	3277	Warrnambool City Council	Unsubdivided	52101	South-West Coast	77	Western Victoria
Allendale	3364	Hepburn Shire Council	Creswick	56404	Ripon	72	Western Victoria
Allestree	3305	Glenelg Shire Council	Unsubdivided	51701	South-West Coast	77	Western Victoria
Alma	3465	Central Goldfields Shire Council	Paddys Ranges	56303	Ripon	72	Western Victoria
Almonds	3727	Moira Shire Council	Unsubdivided	52901	Ovens Valley	65	Northern Victoria
Almurta	3979	Bass Coast Shire Council	Leadbeater	53404	Bass	3	Eastern Victoria
Alphington	3078	Darebin City Council	Rucker	50803	Northcote	63	Northern Metropolitan
Alphington	3078	Yarra City Council	Langridge	51301	Northcote	63	Northern Metropolitan
Altona	3018	Hobsons Bay City Council	Cherry Lake	50901	Altona	2	Western Metropolitan
Altona Meadows	3028	Hobsons Bay City Council	Cherry Lake	50901	Altona	2	Western Metropolitan
Altona Meadows	3028	Hobsons Bay City Council	Wetlands	50903	Altona	2	Western Metropolitan
Altona North	3025	Hobsons Bay City Council	Cherry Lake	50901	Altona	2	Western Metropolitan
Altona North	3025	Hobsons Bay City Council	Cherry Lake	50901	Williamstown	86	Western Metropolitan
Altona North	3025	Hobsons Bay City Council	Strand	50902	Williamstown	86	Western Metropolitan
Alvie	3249	Colac Otway Shire Council	Unsubdivided	51501	Polwarth	67	Western Victoria
Amherst	3371	Central Goldfields Shire Council	Paddys Ranges	56303	Ripon	72	Western Victoria
Amor	3825	Baw Baw Shire Council	North	53503	Narracan	58	Eastern Victoria
Amphitheatre	3468	Pyrenees Shire Council	Avoca	51901	Ripon	72	Western Victoria
Amphitheatre	3468	Pyrenees Shire Council	De Cameron	51903	Ripon	72	Western Victoria

Appendix 4C: ICD coding: master file

There are 19,454 ICD-10-AM codes in the master file. These were used against our patients to match the conditions. An example of diabetes mellitus is shown below. There are 182 ICD-10-AM dedicated code to demonstrate conditions associated with diabetes mellitus (Type I and II). The first 30 codes are shown below.

Appendix 4C: **An example of ICD coding for diabetes mellitus**

ICD coding	Description
E10.	Type 1 diabetes mellitus
E10.0	Type 1 diabetes mellitus with hyperosmolarity
E10.01	Type 1 diabetes mellitus with hyperosmolarity without nonketotic hyperglycaemic-hyperosmolar coma (NKHHC)
E10.02	Type 1 diabetes mellitus with hyperosmolarity with coma
E10.1	Type 1 diabetes mellitus with acidosis
E10.11	Type 1 diabetes mellitus with ketoacidosis, without coma
E10.12	Type 1 diabetes mellitus with ketoacidosis, with coma
E10.13	Type 1 diabetes mellitus with lactic acidosis, without coma
E10.14	Type 1 diabetes mellitus with lactic acidosis, with coma
E10.15	Type 1 diabetes mellitus with ketoacidosis, with lactic acidosis, without coma
E10.16	Type 1 diabetes mellitus with ketoacidosis, with lactic acidosis, with coma
E10.2	Type 1 diabetes mellitus with kidney complication
E10.21	Type 1 diabetes mellitus with incipient diabetic nephropathy
E10.22	Type 1 diabetes mellitus with established diabetic nephropathy
E10.29	Type 1 diabetes mellitus with other specified kidney complication
E10.3	Type 1 diabetes mellitus with ophthalmic complication
E10.31	Type 1 diabetes mellitus with background retinopathy
E10.32	Type 1 diabetes mellitus with preproliferative retinopathy
E10.33	Type 1 diabetes mellitus with proliferative retinopathy
E10.34	Type 1 diabetes mellitus with other retinopathy
E10.35	Type 1 diabetes mellitus with advanced ophthalmic disease
E10.36	Type 1 diabetes mellitus with diabetic cataract

Appendix 4D: ICD-10-AM codes for used for acute spinal cord injury (SCI)

The codes for spinal cord injury (acute) will vary depending on the site. A list of injuries covered in the study are shown below:

Spinal cord injury	
Spinal cord	T09.3
with nerves involving multiple body regions	T06.1
Cervical (neck)	S14.10
with anterior cord syndrome	S14.13
central cord syndrome	S14.12
complete lesion of cord	S14.11
incomplete cord syndrome NEC	S14.13
posterior cord syndrome	S14.13
Functional level Cervical NEC S14.70	
C1	S14.71
C2	S14.72
C3	S14.73
C4	S14.74
C5	S14.75
C6	S14.76
C7	S14.77
C8	S14.78
Thoracic S24.10	S24.10
complete lesion of cord	S24.11
anterior cord syndrome	S24.12
central cord syndrome	S24.12
incomplete cord syndrome	S24.12
posterior cord syndrome	S24.12
Functional level Thoracic NEC S24.70	
T1	S24.71
T2–T3	S24.72
T4–T5	S24.73
T6–T7	S24.74
T8–T9	S24.75
T10–T11	S24.76
T12	S24.77
Lumbar (conus medullaris) S34.1	
Functional level Lumbar NEC S34.70	
L1	S34.71
L2	S34.72
L3	S34.73
L4	S34.74
L5	S34.75
sacrum	S34.76

Appendix 4E: Charlson Comorbidity Index

Comorbidity	**ICD-10-AM codes**
1. Cancer	C00, C01, C02, C03, C05, C06, C40, C41, C43, C45, C46, C47, C48, C49, C70, C71, C72, C73, C74, C75, C76, C80, C81, C82, C83, C84, C85, C883, C887, C889, C900, C901, C91, C92, C93, C940, C941, C942, C943, C95, C9451, C96, C947
2. Congestive heart failure	I50
3. Connective tissue disease	M050, M051, M052, M053, M058, M059, M059, M060, M063, M069, M32, M332, M34, M353
4. Cerebrovascular accident	G450, G451, G452, G454, G458, G459, G46, I60, I62, I63, I64, I65, I66, I670, I671, I672, I674, I675, I676, I677, I678, I679, I69, I681, I682, I688
5. Dementia	F00, F01, F02, F03, F051
6. Diabetes, complicated	E102, E103, E104, E112, E113, E114, E132, E133, E134, E142, E143, E144
7. Diabetes, uncomplicated	E101, E105, E109, E111, E115, E119, E131, E135, E139, E141, E149, E145,
8. HIV	B20, B21, B22, B23, B24
9. Liver disease (mild to moderate)	K702, K703, K746, K745, K717, K73, K740, K742, K743, K744
10. Metastatic cancer	C77, C78, C79, C80
11. Myocardial Infarct	I21, I22, I252
12. Hemiplegia	G81, G041, G820, G821, G822
13. Ulcer disease	K25, K26, K27, K28
14. Chronic pulmonary disease	J40, J41, J42, J43, J44, J45, J46, J47, J60, J61, J62, J63, J64, J65, J66, J67
15. Peripheral vascular disease	I71, I739, I790, R02, Z958, Z959
16. Chronic renal disease	N01, N03, N18, N19, N25, N052, N053, N054, N055, N056, N056, N072, N073, N074
17. Moderate to severe liver disease	K721, K729, K766, K767

Appendix 4Fa: Elixhauser Comorbidity Index (a)

Elixhauser Comorbidity Index is based on hospital setting. It has 30 indexes. SCI specific comorbidities were included (rows 31-40).

Medical conditions	**ICD-10-AM codes**
1. Congestive heart failure	I19.9, I11.0., I13.0., I13.2., I25.5., I42.0., I42.5-I42.9, I43., I50.
2. Cardiac arrhythmias	I44.1-I44.3, I45.6, I45.9, I47-I49, R00.0, R00.1, R00.8, T82.1, Z45.0, Z95.0
3. Valvular disease	A52.0, I05., I06., I07., I08., I09.1, I09.8, I34.-I39., Q23.0-Q23.3, Z95.2, Z95.4
4. Pulmonary circulation disorders	I26., I27., I28.0., I28.8., I28.9
5. Peripheral vascular disorders	I70., I71., I73.1, I73.8, I73.9, I77.1, I79.0, I79.2, K55.1, K55.8, K55.9, Z95.8, Z95.9
6. Hypertension (combined)	I10., I11., I12, I13., I15.
7. Paralysis	G04.1, G11.4, G80.1, G81., G82., G83.0-G83.4, G83.9
8. Other neurological conditions	G10.-G13., G20., G21., G25.4, G25.5, G31.2, G31.8, G31.9, G32., G35.-G37., G40., G41., G93.1, G93.4, R47.0, R56.
9. Chronic pulmonary disease	I27.8, I27.9, J40-J47., J60.-J68.4., J70.1, J70.3
10. Diabetes, uncomplicated [DM]	E10.0, E10.1, E10.9, E11.0, E11.1, E11.9, E12.0, E12.1, E12.9, E10.0, E13.1, E13.9, E14.0, E14.1, E14.9
11. Diabetes, complicated [DMc]	E10.2-E10.8, E11.2-E11.8, E12.2-E12.8, E13.2-E13.8, E14.2-E14.8
12. Hypothyroidism	E00., E00.1, E00.2, E00.3, E89.0
13. Renal failure [RF]	I12.0, I13.1, N18., N19., N25., Z49.0, Z49.1, Z49.2, Z94.0, Z99.2
14. Liver disease [LD]	B18., I85., I86.4, I98.2, K70., K71.1 K71.3, K71.4, K71.5, K71.7. K72., K73., K74., K76.0-K76.9. Z94.4
15. Peptic ulcer disease	K25.7, K25.9, K26.7, K26.9, K27.7, K27.9, K28.7, K28.9
16. HIV or AIDS	B20., B21., B22., B23., B24.
17. Lymphoma	C81., C82., C83., C84., C85., C88., C90.0, C90.2, C96.
18. Metastatic cancer	C77., C78., C79., C80.
19. Solid tumor without metastasis	C00.– C26., C30., C31.-C34., C37.-C41., C43., C45.-C76., C97.
20. Rheumatic or connective tissue disease	L94.0, L94.1, L94.3,

	M05., M06., M08., M12.0, M12.3, M30., M31.0, M31.2, M31.3, M32.-M35., M45., M46.1, M46.8, M46.9
21. Coagulopathy	D65.-D68., D69.1, D69.3, D69.4, D69.5, D69.6
22. Obesity	E66.
23. Weight loss	E40.-E46., R63.4., R64.
24. Fluid and electrolyte disorders	E22.2, E86., E87.
25. Blood loss anaemia	D50.0
26. Deficiency anaemia	D50.8., D50.9., D51., D52., D53.
27. Alcohol abuse	F10., E52., G62.1, I42.6, K29.2, K70.0, K70.3, K70.9, T51., Z50.2, Z71.4, Z72.1
28. Drug abuse	F11.-F19., Z71.5., Z72.2
29. Psychoses	F20., F22.-F25., F28., F29., F30.2, F31.2, F31.5
30. Depression	F20.4., F31.3., F31.4., F32., F33., F34.1., F41.2., F43.2
31. Delirium	F05.9
32. Personality disorder	F60.3, F60.6-F60.8, F63., F64., F93., F95., F98.
33. Autonomic Dysreflexia (AD)	G90.4
34. Bowl complications	K59.0., K60.1-K60.9, K61.0-K61.4
35. Cellulitis	L03.1, L03.10, L03.11, L03.9
36. Dementia or Alzheimer	F00., F01., F02., F05.1
37. Hypotension	G90.3, I95.0, I95.1, I95.8, I95.9
38. Pressure ulcers	L02.3, L02.4, L89., L97.
39. Sleep apnoea	G47.30, G47.31, G47.32, G47.33, G47.39
40. Urinary complications	N13., N14., N20., N21., N30.-N37., N39.-N42., R31.-R39.

Appendix 4Fb: Elixhauser Comorbidity Index (b)

Below is a snap shot of patients that were subjected to Elixhauser comorbidity index. There were 40 indexes. First column shows total count of comorbidities for that patient.

i. Rows 1 to 10

Count	1. Congestive heart failure	2. Cardiac arrhythmias	3. Valvular disease	4. Pulmonary circulation Disorders	5. Peripheral vascular disorders	6. Hypertension (combined)	7. Paralysis	8. Other neurological conditions	9. Chronic pulmonary disease	10. [DM]
1	0	0	0	0	0	0	0	0	0	0
4	0	0	0	0	0	1	1	0	0	0
4	0	0	0	0	0	0	0	1	0	0

ii. Rows 11-20

11. [DMc]	12. Hypothyroidism	13. [RF]	14. [LD]	15. Peptic ulcer disease excluding bleeding	16. AIDS	17. Lymphoma	18. Metastatic cancer	19. Solid tumour without metastasis	20. Rheumatic or connective tissue disease
0	0	0	0	0	0	0	0	0	0
1	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	1	0	0	0	0	0	0	0

iii. Rows 21-30

21. Coagulopathy	22. Obesity	23. Weight loss	24. Fluid and electrolyte disorders	25. Blood loss anaemia	26. Deficiency anaemia	27. Alcohol abuse	28. Drug abuse	29. Psychoses	30. Depression
0	0	0	0	0	0	1	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	0
0	0	0	2	0	0	0	0	0	2

iv. Rows 31-40 _ SCI specific comorbidities

31. Delirium	32. Personality disorder	33. Autonomic dysreflexia [AD]	34. Bowel complications [BC]	35. Cellulitis	36. Dementia or Alzheimer's	37. Hypotension	38. Pressure ulcers	39. Sleep apnoea	40. Urinary complications [UC]
0	0	0	0	0	0	0	0	0	0
0	0	0	0	0	0	0	0	0	1
0	0	0	0	0	0	0	1	1	1
0	0	0	1	0	0	0	1	0	1

Appendix 5: Time Series Analysis I - Austin pilot study: (Appendices 5A – 5H)

Appendix 5A: Trends in male and female admissions

Year	Male	Male Trend	%Male	Female	Female Trend	% Female	Ratio	Total (F&M)
1998	29		74	10		26	2.9	39
1999	60	91	78	17	25	22	3.5	77
2000	50	67	79	13	23	21	3.8	63
2001	56	67	77	17	23	23	3.3	73
2002	103	103	80	26	21	20	4	129
2003	115	125	86	18	19	14	6.4	133
2004	115	136	81	27	21	19	4.3	142
2005	105	135	85	19	17	15	5.5	124
2006	99	132	81	23	20	19	4.3	122
2007	96	127	83	19	15	17	5.1	115

Appendix 5B: Total patient admissions from 1 July 1998 to 30 June 2008

Year	Male	Female	Ratio
1998	29	10	2.9
1999	60	17	3.5
2000	50	13	3.8
2001	56	17	3.3
2002	103	26	4:1
2003	115	18	6.4
2004	115	27	4.3
2005	105	19	5.5
2006	99	23	4.3
2007	96	19	5.1
2008	31	1	incomplete

Appendix 5C: Austin pilot study: separation by principal diagnosis

ICD	Description	Count	%
S14.70	Injury of cervical SC, level unspecified	55	0.05
S14.71	Injury of cervical SC at C1 level	7	0.01
S14.72	Injury of cervical SC at C2 level	10	0.01
S14.73	Injury of cervical SC at C3 level	19	0.02
S14.74	Injury of cervical SC at C4 level	82	0.08
S14.75	Injury of cervical SC at C5 level	116	0.11
S14.76	Injury of cervical SC at C6 level	64	0.06
S14.77	Injury of cervical SC at C7 level	21	0.02
S14.78	Injury of cervical SC at C8 level	9	0.01
S24.70	Injury of thoracic SC, level unspecified	13	0.01
S24.71	Injury of thoracic SC, at T1 level	15	0.01
S24.72	Injury of thoracic SC, at T2-T3 level	9	0.01
S24.73	Injury of thoracic SC, at T4-T5 level	40	0.04
S24.74	Injury of thoracic SC, at T6-T7 level	27	0.03
S24.75	Injury of thoracic SC, at T8-T9 level	34	0.03
S24.76	Injury of thoracic SC, at T10-T11 level	24	0.02
S24.77	Injury of thoracic SC, at T12 level	40	0.04
S34.70	Injury of lumbar SC, level unspecified	15	0.01
S34.71	Injury of SC at L1	46	0.04
S34.72	Injury of SC at L2	20	0.02
S34.73	Injury of SC at L3	16	0.01
S34.74	Injury of SC at L4	7	0.01
S34.75	Injury of SC at L5	2	0.00
S34.76	Injury of SC at sacral level	10	0.01
T91.3	Sequelae of injury of spinal cord	371	0.35
Total		1072	1.00

Appendix 5D: Austin pilot study: main reasons for readmission

ICD	Description	% of readmissions	Total. episodes
N39.0	Urinary tract infection	19.6%	830
S42, S52	Upper or lower limb fracture	15.6%	661
L89	Pressure ulcer	13.6%	578
J98.	Respiratory complication	13.2%	559
F32	Mental disorders	8.6%	366
K59.0	Bowel complication	6.3%	268
G47.	Sleep disorders	4.5%	189
N31	Neurogenic bladder	3.2%	137
R50.9	Fever (unspecified)	2.9%	125
N39.3	Urinary incontinence	2.4%	100
N30.0	Cystitis	1.7%	74
R33	Urinary retention	1.6%	68
N20	Urinary calculi	1.4%	58
I80	Venous thrombosis	1.3%	57
L03.1 +	Cellulitis	1.3%	55
G90.4	Autonomic dysreflexia	0.9%	38
I26	Pulmonary embolus	0.8%	35
N13	Uropathy	0.3%	13
C67.0-67.9	Bladder cancer	0.3%	13
N41.0	Prostatitis	0.1%	5
R52.1	Chronic pain	0.1%	5
N41.0	Urinary retention	0.1%	4
		100.00%	4242

Appendix 5E: Austin pilot study: % readmissions

No. of readmissions	Patient count (%)	Patient count
1	34.1%	188
2	15.8%	87
3	23.2%	128
4	8.3%	46
5	5.3%	29
6	3.4%	19
7	3.3%	18
8	1.8%	10
9	1.5%	8
10	1.1%	6
11	0.5%	3
12	0.5%	3
13	0.2%	1
14	0.0%	0
15	0.4%	2
16	0.2%	1
17	0.2%	1
18	0.2%	1
	100.0%	551

Appendix 5F: Austin pilot study: Separation by Health services

Separation by Health Services	16-30 years		31-45 years		46-60 years		61-75 years		76+ years		Total
	M	F	M	F	M	F	M	F	M	F	
Gippsland	25	5	20	7	24	5	9	5	4	2	106
Hume	18	1	17	3	16	2	8	1	1	1	68
Grampians	14	2	7	4	10	1	6	2	1	0	47
Loddon Mallee	12	2	13	1	15	2	8	0	5	3	61
Metropolitan*	134	19	143	25	123	24	82	34	34	7	625
Barwon-South Western	10	2	10	2	12	4	6	1	2	2	51
Tasmania	19	6	9	4	9	4	4	2	2	1	60
NSW	9	0	4	1	7	0	3	0	1	1	26
Unknown postcodes	7	1	5	0	1	1	0	0	0	1	16
Other	2	0	4	0	3	2	1	0	0	0	12
Total	135	153	114	165	121	144	79	93	23	45	1072

Appendix 5G: Austin pilot study: Separation by Metropolitan areas

Age Range	16-30 years		31-45 years		46-60 years		61-75 years		76+ years		Total
	M	F	M	F	M	F	M	F	M	F	
Eastern Metropolitan	38	9	47	10	38	10	26	17	12	3	210
Northern Metropolitan	38	4	33	2	36	3	21	7	8	0	152
Southern Metropolitan	24	3	25	5	20	5	16	4	7	3	112
Western Metropolitan	23	0	24	5	17	2	9	5	3	0	88
South-Eastern Metropolitan	11	3	14	3	12	4	10	1	4	1	63
Total	134	19	143	25	123	24	82	34	34	7	625

Appendix 5H: Austin pilot study: WIES

Qualifying ICD Code	WIES	Mean -WIES	Total days ex HITH	Ave LOS ex HITH	Patients
Cervical level unspecified	575	9.6	1,344	61	55
C1	282	1.2	706	420	7
C2	244	1.7	623	154	10
C3	636	3.3	1,756	200	19
C4	2,754	14.3	8,048	216	82
C5	3,586	20.2	10,912	193	116
C6	2,142	11.1	6,726	192	64
C7	544	3.7	1,716	187	21
C8	134	1.6	395	146	9
Thoracic level unspecified	235	2.3	1,065	107	13
T1	305	2.6	804	104	15
T2/T3	362	1.6	857	275	9
T4/T5	1,444	7.0	4,168	336	40
T6/T7	948	4.7	2,977	358	27
T8/T9	618	5.9	2,071	218	34
T10/T11	412	4.2	1,467	200	24
T12	459	7.0	1,745	92	40
Lumbar level unspecified	152	2.6	583	86	15
L1	680	8.0	2,690	108	46
L2	370	3.5	1,634	140	20
L3	196	2.8	871	97	16
L4	100	1.2	483	116	7
L5	11	0.3	22	22	2
Sacrum	90	1.7	242	64	10
Sequelae of injury	2,189	64.6	7,930	6	371
Total	19,468	0.0	61,834	4,096	

Appendix 6: Time Series Analysis II - Cohort from three hospitals (Appendices 6A-6H)

Appendix 6A: Separation by principal diagnosis 2000-2014 expressed as %

ICD code	Count	Principal diagnosis	Count	%
S14.0	48	Concussion & Oedema, csc	48	1.8%
S14.10	98	Injury of cervical SC	98	3.7%
S14.11	48	Complete lesion of csc	48	1.8%
S14.12	88	Central cord syndrome	88	3.3%
S14.13	65	Incomplete cord syndrome	65	2.5%
S14.20	1	Injury of nerve root of csc	1	0.0%
S14.3	3	Injury of brachial plexus	3	0.1%
S14.70	333	Functional, C-unspecified	333	12.7%
S14.71	25	C1	25	1.0%
S14.72	38	C2	38	1.4%
S14.73	58	C3	58	2.2%
S14.74	145	C4	145	5.5%
S14.75	199	C5	199	7.6%
S14.76	145	C6	145	5.5%
S14.77	54	C7	54	2.1%
S14.78	17	C8	17	0.6%
S24.0	200	Concussion & Oedema, tsc	200	7.6%
S24.10	87	Injury of tsc unspecified	87	3.3%
S24.11	38	Complete lesion of tsc	38	1.4%
S24.12	37	Incomplete cord syndrome of tsc	37	1.4%
S24.2	1	Injury of nerve root of tsc	1	0.0%
S24.70	88	Functional, T-unspecified	88	3.3%
S24.71	26	T1	26	1.0%
S24.72	27	T2/T3	27	1.0%
S24.73	86	T4/T5	86	3.3%
S24.74	71	T6/T7	71	2.7%
S24.75	54	T8/T9	54	2.1%
S24.76	50	T10/T11	50	1.9%
S24.77	96	T12	96	3.7%
S34.0	9	Concussion & Oedema, lumbar spinal cord	9	0.3%
S34.1	40	Conus medullaris	40	1.5%
S34.10	5	Injury of lumbar spinal cord	5	0.2%
S34.2	54	Injury of nerve root of L & sacral spinal cord	54	2.1%
S34.3	27	Injury of cauda equina	27	1.0%
S34.4	10	Injury of lumbosacral plexus	10	0.4%
S34.5	1	Injury of L, Sacral and pelvic sympathetic nerve	1	0.0%
S34.6	4	Injury of peripheral nerve	4	0.2%
S34.70	100	Functional, L-unspecified	100	3.8%
S34.71	62	L1	62	2.4%

S34.72	32	L2	32	1.2%
S34.73	19	L3	19	0.7%
S34.74	12	L4	12	0.5%
S34.75	9	L5	9	0.3%
S34.76	12	L6	12	0.5%
T09.3	7	SCI-unspecified	7	0.3%
			2629	

Appendix 6B: Cohort: % readmission.

Total no. of patients	**Total no patients**	**%**
18	1	0.1
17	3	0.4
16	9	1.3
15	3	0.4
14	7	1.0
13	4	0.6
12	8	1.1
11	11	1.6
10	15	2.1
9	21	3.0
8	31	4.4
7	21	3.0
6	33	4.7
5	24	3.4
4	51	7.3
3	82	11.7
2	163	23.2
1	192	27.3
Total	679	100.0

Appendix 6C: Mean Length Of Stay by principal diagnosis

ICD-10-AM	Medical Description	Total patients	% PDx	Mean
S14.0	Conc & Oedema, Cervical	48.0	1.8%	5.3
S14.1X	Cervical unspecified	302.0	11.5%	4.8
S14.70	Functional SCI, C-unspecified	334.0	12.7%	10.7
S14.71	C1	25	1.0%	7.5
S14.72	C2	38	1.4%	5.6
S14.73	C3	58	2.2%	7.9
S14.74	C4	144	5.5%	6.9
S14.75	C5	199	7.6%	6.5
S14.76	C6	145	5.5%	8.2
S14.77	C7	54	2.1%	8.2
S14.78	C8	17	0.6%	11.1
S24.0	Conc & Oedema, Thoracic	202.0	7.7%	7.9
S24.1	Thoracic unspecified	161.0	6.1%	4.9
S24.70	Functional SCI, T-unspecified	92.0	3.5%	11.5
S24.71	T1	24	0.9%	5.8
S24.72	T2/T3	26	1.0%	5.0
S24.73	T4/T5	86	3.3%	9.3
S24.74	T6/T7	71	2.7%	6.2
S24.75	T8/T9	54	2.1%	5.1
S24.76	T10/T11	50	1.9%	5.6
S24.77	T12	96	3.7%	8.8
S34.0	Conc & Oedema, Lumbar	9.0	0.3%	8.7
S34.1	Lumbar unspecified	140.0	5.3%	11.5
S34.70	Functional SCI, L-unspecified	102.0	3.9%	13.5
S34.71	L1	62	2.4%	3.7
S34.72	L2	31	1.2%	9.6
S34.73	L3	19	0.7%	4.4
S34.74	L4	12	0.5%	3.8
S34.75	L5	9	0.3%	5.6
S34.76	Functional SCI, Sacrum	12	0.5%	9.4
T09.x	SCI-unspecified	7.0	0.3%	0.4
Total	Patients	**2629.0**		

Appendix 6D(a): Risk profile: High readmissions - (21 to 56 readmissions)

Case 1

An 81-year-old female was diagnosed with incomplete cord syndrome and functional cervical injury unspecified. Prior to injury there was no record of comorbidities or risk factors. She developed kidney disease within three months of her traumatic spinal cord injury, subsequently came in to the hospital for dialysis as an outpatient for 56 times over 1.5 years. No further information was provided after discharge on 26th of March, 2011.

56 readmissions – 81-year-old female
Total period of time examined: (Sept 2010 – Mar 2011)
Principal diagnosis: Incomplete cord syndrome (S14.13 & functional spinal cord injury, cervical level unspecified (S14.70)
Comorbidities: None recorded
Risk factors: None recorded

[Between first admission and last discharge, patient came in every day]
Cumulative intervals: Calculated from first discharge date to next admission date.

First admission	Last discharge	Cumulative intervals (#)	No of Admissions	Reasons for readmission
11-Sep-10	**15-Nov-10**			**S14.13 & S14.70**
16-Nov-10	14-Dec-10	1 month	12 admissions with interval of 2 to 5 days	Extracorporeal dialysis
16-Dec-11	15-Jan-11	2 months	13 admissions with interval of 2 to 3 days	Extracorporeal dialysis
18-Jan-11	15-Feb-11	3 months	12 admissions with interval of 2 to 3 days	Extracorporeal dialysis
17-Feb-11	15-Mar-11	4 months	11 admissions with interval of 2 to 3 days	Extracorporeal dialysis
17-Mar-11	26-Mar-11	5 months	5 admissions with interval of 2 to 3 days	Extracorporeal dialysis

Case 2

An 83-year-old male was diagnosed with injuries to thoracic spinal cord (S24.0), had pre-existing conditions of anaemia & cardiac implant device. Cancer was recorded at the 51st readmission, 3 years after the initial trauma. The first readmission was 2.4 years after first discharge. He came in 50 times with intervals of 2 to 3 days with soft tissue disorder, pressure ulcer and varicose veins in the lower extremities.

51 readmissions – 83-year-old male

Total period of time examined: (Oct 2011 – Dec 2014)

Principal diagnosis: Injuries to thoracic spinal cord (S24.0).

Comorbidities: Anaemia, and cardiac implant device. Cancer recorded at the 51st readmission, 3 years after the initial trauma.

Risk factors: None recorded

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
20-Oct-11	**10-Nov-11**			**S24.0**
07-Apr-14	11-Apr-14	2.4 years	5	Radiology procedure (5), soft tissue disorder (5) & varicose veins lower extremities with ulcer (5)
14-Apr-14	17-Apr-14	2.4 years	4	Radiology procedure (4), soft tissue disorder (4) & varicose veins lower extremities with ulcer (4)
22-Apr-14	24-Apr-14	2.5 years	3	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
28-Apr-14	30-Apr-14	2.5 years	3	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
01-May-14	02-May-14	2.5 years	2	Pressure ulcer, soft tissue disorder, varicose veins lower extremities with ulcer
05-May-14	09-May-14	2.5 years	5	Pressure ulcer, soft tissue disorder, varicose veins lower extremities with ulcer
12-May-14	16-May-14	2.5 years	5	Pressure ulcer (5), soft tissue disorder (5), varicose veins lower extremities with ulcer (5)
19-May-14	23-May-14	2.5 years	5	Radiology procedure (5), soft tissue disorder (5) & varicose veins lower extremities with ulcer (5)
26-May-14	30-May-14	2.5 years	5	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
02-Jun-14	06-Jun-14	2.6 years	5	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
10-Jun-14	13-Jun-14	2.6 years	4	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
17-Jun-14	20-Jun-14	2.6 years	4	Radiology procedure (3), soft tissue disorder (3) & varicose veins lower extremities with ulcer (3)
03-Nov-14	16-Dec-14	3.1 years	1	B-cell lymphoma, atrial fibrillation and flutter & varicose veins lower extremities with ulcer

Case 3

A 37-year-old female was admitted 50 times with existing comorbidities of leukemia, mental disorder and type 2 diabetes mellitus, with risk factor of smoking. She was admitted 30 times in the first six months with follow up care relating to existing leukemia. Within a year she developed acute kidney disease and was admitted 20 times within six months due to chemotherapy.

50 readmissions – 37-year-old female
Admission Period: (Dec 2013 – Dec 2014) LOS (41 days) ICU (no information)
Principal diagnosis: Injuries to lumbar spine unspecified (S34.70)
Comorbidities: Lymphoid leukemia, mental disorder (anxiety, depressions), type 2-diabetes mellitus
Risk factors: Smoking

First admission	Last discharge	Cumulative intervals	No of admissions	Reasons for readmission
12-Dec-13	**30-Jan-14**			S34.70
01-Feb-14	27-Feb-14	1 month	4 (once a week)	Lymphoid leukaemia (4) & musculoskeletal disorder (4)
18-Mar-14	18-Mar-14	2 month2	1	Musculoskeletal disorder
04-Apr-14	16-May-14	2 months	1	Bowel complications, respiratory infection & musculoskeletal disorder
19-May-14	30-May-14	3 months	6 (every 2nd day)	Pharmacotherapy session for leukaemia (6)
02-Jun-14	20-Jun-14	3 months	8 (interval of 2 to 3 days)	Pharmacotherapy session for leukaemia (8)
22 -Jun-14	24-Jun-14	4 months	1	Acute kidney failure, fever of unknown & musculoskeletal disorder
25-Jun-14	21-Jul-14	4 months	9 (interval of 1 to 4 days)	Pharmacotherapy session for leukaemia (9)
25-Sep-14	30-Sep-14	7 months	1	Kidney failure, bowel complications, gastritis & duodenitis
03-Oct-14	23-Oct-14	7 months	1	Kidney failure, heart attack, musculoskeletal disorder, & unspecified haematuria
10-Nov-14	15-Dec-14	8 months	16 (interval of 2 to 5 days)	Musculoskeletal disorder & pharmacotherapy session for leukaemia (16)
17-Nov-14	17-Nov-14	9 months	1	Musculoskeletal disorder, pharmacotherapy session for leukaemia & prophylactic pharmacotherapy
19-Dec-14	19-Dec-14	9 months	1	Prophylactic pharmacotherapy

Case 4

A 42-year-old male with existing hypotension and mental disorder, with risk factors of alcohol and smoking. He developed skin cancer in the 6th year after spinal cord injury. Please note readmissions due to respiratory infections 4 times and ten readmissions due to Urinary Tract Infections (UTI).

45 readmissions – 42-year-old male
Admission Period: (Sept 2004 – May 2014) LOS (57 days), ICU (169 hours)
Principal diagnosis: Functional level thoracic spinal cord injury, T1 (S24.71)
Comorbidities: Hypotension, mental disorder, skin cancer diagnosed in the 6th year after SCI.
Risk factors: alcohol dependence, smoking

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
27-Sep-04	**23-Nov-04**			**S24.11 & S24.71**
29-Nov-04	19-Jan-05	3 months	2	Cellulitis, pneumonia (1) & UTI (1)
18-Feb-05	18-Feb-05	6 months	1	Cellulitis & UTI
10-Nov-05	30-Nov-05	2 years	2	Mental disorder (schizophrenia) (1), pressure ulcer (1), respiratory infection & urinary calculi (1)
24-Mar-06	10-Apr-06	3 years	2	Pneumonia (1), urinary calculi & UTI (1)
01-Jul-08	30-Jul-08	4 years	3	Burns (1), pressure ulcer (1) & UTI (1)
30-Mar-09	28-Sep-09	5 years	4	Haematuria (1), pneumonia (1), pressure ulcer (1) & UTI (1)
19-Jan-10	24-Sep-10	6 years	9	Autonomic dysreflexia (1), cellulitis (1), neurogenic bladder (1), pneumocystis (1), pneumonia (1), skin cancer (1) & UTI (4)
14-Feb-11	19-Oct-11	7 years	7	Cystitis (2), haematuria (2), retention of urine (1) & UTI (2)
15-Nov-11	30-Nov-12	8 years	4	Cystitis (1), somatoform-mental disorder (1), UTI (2)
28-Dec-12	08-Oct-13	9 years	9	Autonomic dysreflexia (1), injury of urethra (2), UTI (6)
23-May-14	31-May-14	10 years	2	Pneumonia (2) & UTI (2)

Case 5

A 57-year-old male had 38 admissions over an 8-year period, with frequent readmission due to sleep apnoea (11 times) and UTI (15 times). In year 2, the patient developed acute kidney failure and was admitted 12 times for kidney-related issues. Please note existing conditions of hyper- and hypotension, with risk factor of smoking. The patient was admitted with a heart attack in year 7 post-SCI.

38 readmissions – 57-year-old male
Admission Period: (Sept 2002 – Dec 2010)
Principal diagnosis: Complete lesion of cervical spinal cord (S14.11), functional spinal cord injury, cervical 5 (S14.75).
Comorbidities: hypertension and hypotension (1 year later)
Risk factors: smoking

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
7-Sep-02	**10-Apr-03**			**S14.13 & S14.75**
26-Apr-03	07-May-03	1 month	5	Sleep apnoea (4) & UTI (1)
09-Jun-03	15-Jul-03	3 months	4	Sleep apnoea (2) & UTI (2)
24-Aug-03	24-Aug-03	6 months	2	Bowel complications (1), neurogenic bladder (1) & UTI (1)
02-Nov-03	08-Feb-04	1 year	5	Bowel complications (4), sleep apnoea (1) & UTI (1)
27-Apr-04	10-Mar-05	2 years	12	Acute kidney failure (2), bowel complications (1), cystitis (1), neurogenic bladder (3) & UTI (5)
21-Jun-05	07-Dec-05	3 years	6	Bowel complications (2), headache (1) & UTI (3)
31-Mar-07	31-Mar-07	4 years	1	UTI
30-Jul-09	17-Aug-09	7 years	2	Atrial fibrillation and flutter (1) & constipation (1)
01-Dec-10	01-Dec-10	8 years	1	Mechanical fitting of urinary catheter

Case 6

A 72-year-old female, with pre-existing condition of blood cancer (non-Hodgkin's disease) prior to traumatic spinal cord injury, was admitted 34 times over a 12-year period. She developed kidney failure 3 months after the accident, and was readmitted fortnightly over the next year for the follow-up treatment of her kidney condition and cancer. She also had hypertension, and developed a myocardial infarct six months after discharge.

34 readmissions – 72-year-old male
Admission Period: (July 2012 – Sept 2014)
Principal diagnosis: Concussion and oedema of thoracic spinal cord (S24.0)
Comorbidities: Type2-diabetes mellitus, hypertension, blood cancer (NHL)
Risk factors: none

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
27-Jul-12	**10-Aug-12**			**S24.0**
08-Oct-12	03-Dec-12	3 months	4	Chronic kidney failure (4), oral mucositis ulcerative (1) & respiratory failure (1)
19-Dec-12 09-Jan-13	19-Dec-12 09-Jan-13	4 months	2	Chronic kidney disease (1), blood cancer (2), pharmacotherapy session for neoplasm (2)
11-Jan-13	17-Jan-13	4 months	1	Myocardial infarct and heart attack
29-May-13	17-Jul-13	1 year	2	Cancer (2), chronic kidney disease (1)
04-Sep-13	30-Jul-14	2 years	19 (2x a month)	Follow up for anaemia, cancer and chronic kidney disease
27-Aug-14	24-Sep-14	3 years	4 (2x a month)	Follow up for anaemia, cancer and chronic kidney disease

Case 7

A 34-year-old male smoker was admitted 33 times over a period of 6 years. The first readmission was after 3 months for orthopaedic follow up. He was readmitted within six months for attempted suicide and disorders of bone. He was admitted 29 times between August and October 2014 for pressure ulcer and necrosis in the lower limb as well as disorders from the use of psychoactive substances.

33 readmissions – 34-year-old male
Admission Period: (Sept 2008 – Oct 2014)
Principal diagnosis: Functional spinal cord injury, lumbar level unspecified (S34.70)
Comorbidities: Family history of disease noted (not specified)
Risk factors: Smoking

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
02-Sep-08	**25-Sep-08**			**S34.70**
10-Nov-08	10-Nov-08	3 months	1	Orthopaedic follow up
15-Jan-09	16-Jan-09	6 months	1	Disorders of bone, intentional harm
29-Jan-10	01-Feb-10	2 years	1	Disorders of bone, intentional harm
08-Nov-13	09-Nov-13	5.1 years	1	Prosthetics implant device, surgical operation with implant artificial internal device
18-Aug-14	03-Oct-14	6 years	29 (admitted 5 to 6 days a week:	Pressure ulcer (29) & psychoactive substance use disorder (29)

Case 8

A 70-year-old male with functional cervical injury and incomplete cord syndrome was admitted 30 times over a period of six years. The patient had no underlying comorbidities or risk factors. His main reasons for admissions were due to UTI (11x), bowel complications (4x), respiratory complications (5x) and was admitted due to heart-related issues three times including heart attack and heart stenosis.

30 readmissions – 70-year-old male
Admission Period: (May 2007 – Jun 2013)
Principal diagnosis: Incomplete cord syndrome of cervical spinal cord (S14.13) & Functional spinal cord injury, C4 (S14.74)
Comorbidities: None
Risk factors: None

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
17-May-07	**29-Nov-07**			**S14.13 & S14.74**
13-Feb-08	13-Feb-08	3 months	1	Sleep apnoea & UTI
26-Mar-08	10-May-08	6 months	3	Neurogenic bladder (1), sleep apnoea (1), pressure ulcer (1) & UTI (1)
10-May-08	24-Oct-08	1 year	3	Hemoptysis (1) heart attack (1), localized oedema (1) & urinary incontinence (1)
04-Jul-09	04-Jul-09	2 years	1	Abdominal pain & constipation
06-Jan-10	11-Oct-10	3 years	5	Abdominal pain (1), atrial fibrillation and flutter (1), contact dermatitis (2), contusion of elbow (1), dosalgia, respiratory complications (1) & UTI (2)
28-Dec-10	10-Dec-11	4 years	9	Cholecystitis (2), fever of unknown origin (1), heart attack (2), iron deficiency anaemia, peritonitis (1), respiratory complications (2) & UTI (2)
23-Dec-11	23-Mar-12	5 years	4	Atrial fibrillation and flutter (2), cellulitis (1), fever of unknown origin (1), pulmonary embolism (1), respiratory complications (1), sleep apnoea (3) & UTI (1)
18-Feb-13	14-Jun-13	6 years	4	Aortic (valve) stenosis (1), dosalgia (1), fever unspecified (1), heart attack (1), osteoporosis (1) & UTI (1)

Case 9

A 79-year-old male with functional cervical injury C4, without any comorbidities or risk factors was readmitted 30 times over a period of 8 years and three months. The main concerns were bowel complications (4), stroke in the 3rd year and acute kidney failure. He was admitted eleven times in the 7th year with a range of issues including heart failure, serious pulmonary obstructive disorder and injuries to hip and thigh. He also reported hypotension and hypertension.

30 readmissions – 79-year-old, male
Admission Period: (Sep 2004 – Dec 2012)
Principal diagnosis: Central cord syndrome (S14.12) & functional spinal cord injury, C4 (S14.74)
Comorbidities: Hypotension & hypertension reported in the 7th year
Risk factors: None

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
14-Sep-04	**17-Sep-04**			**S14.12 & S14.74**
28-Jun-05	28-Jun-05	1 year	1	Bowel complications
10-Apr-06	04-May-06	2 years	2	Bowel complications (2), diaphragmatic hernia (1), diverticulitis (1), haemorrhoids unspecified (1) & melaena (1)
27-Feb-07	19-Aug-07	3 years	4	Cataract (2), cerebral ischaemic attack (1) & disease of vocal cord (1)
22-Jan-08	13-Jul-08	4 years	3	Abdominal pain (1), acute kidney failure (1), benign paroxysmal vertigo (1), dorsalgia (1), hereditary & idiopathic neuropathies
13-Jan-09	12-Apr-09	5 years	4	Neurogenic bladder (1), dizziness and giddiness (1), open wound to finger (1) & transient cerebral ischemic attack (1)
27-Feb-10	10-Sep-10	6 years	3	Benign paroxysmal vertigo (1), disorders of eyelid (1) & transient cerebral ischemic attack (1)
07-Oct-10	16-Sep-12	7 years	11	Cerebral infarction (1), dysphasia (1), heart attack (1), injuries of hip and thigh (3), oesophageal obstruction (1), respiratory complications (3), urinary retention (1), UTI (1) & venous thrombosis (1)
09-Nov-12	28-Dec-12	8 years	2	Dysphasia (1), heart attack (1), respiratory infection (1) & urinary retention (1)

Case 10

A 70-year-old male with central cord syndrome and pre-existing cancer of prostate, hypertension and type 2 diabetes mellitus was admitted 28 times over 9 years. Most of his admissions were not related to his cancer but due to SCI-related complications such as polyuria, bowel complications, UTI and chronic kidney disease that he developed 8 years post-injury.

28 readmissions – 70-year-old, male
Admission Period: (May 2003 – Jan 2012)
Principal diagnosis: Central cord syndrome (S14.12)
Comorbidities: Cancer of prostate, type2-diabetes mellitus, hypertension
Risk factors: None

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
12-May-03	**12-Jun-03**			**S14.12**
24-Jun-03	24-Jun-03	1 month	1	Urinary retention
14-Nov-06	1-Mar-07	4 years	4	Follicular disorder (4), spondylopathy (disorders of the vertebrae) (4)
1-Jun-07	1-Jun-07	5 years	1	Polyuria
06-Feb-08	28-May-10	7 years	2	Abdominal pain (1) & tendency to fall (1)
28-Jun-10	11-May-11	8 years	15	Acute pancreatitis (1), cholecystitis (4), chronic kidney disease (2), pressure ulcer (1), uropathy (4) & UTI (3)
30-May-11	30-May-11	9 years	5	Abdominal pain, atrial fibrillation flutter, bowel complication, chronic kidney disease & medical follow up for cancer (prostate)

Case 11

A 56-year-old male with cervical SCI was admitted 27 times over a period of 3 years. He was alcohol dependent, suffered from depression and was a smoker. He was admitted 18 times for liver disease due to alcohol as indicated below.

27 readmissions – 56-year-old, male
Admission Period: (Feb 2007 – April 2009)
Principal diagnosis: Injury of cervical spinal cord, unspecified (S14.10)
Comorbidities: Hypotension, mental disorder (alcohol dependency)
Risk factors: Alcohol dependency & smoking

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
08-Feb-07	**08-Mar-07**			**S14.10**
24-Mar-07	24-Mar-07	1 month	1	Osteomyelitis (1) & pressure ulcer (3)
01-Jun-07	01-Jun-07	6 months	1	Failure and rejection of transplanted tissue
01-Oct-07	01-Feb-08	1 year	3	Bowel complication (3), depression (1), osteomyelitis & pressure ulcer (3)
12-Feb-08	08-Feb-09	2 years	18	Alcoholic liver disease (18), bowel complications (1), cellulitis (2), urinary retention (1) & UTI (1)
12-Feb-09	04-Apr-09	3 years	4	Alcoholic liver disease (1), ascites (1), cellulitis (2), pressure ulcer (2) & respiratory complication (2)

Case 12

A 38-year-old male, diagnosed with incomplete cord syndrome of cervical spinal cord (S14.13) and functional spinal cord injury C4 (S14.74) with risk factor of smoking, was admitted 26 times over a period of 12 years. The main reasons for readmission were UTI, abdominal and bowel complications, pressure ulcer and mechanical problem with catheter.

26 readmissions – 38-year-old male
Admission Period: (Mar 2002 – Mar 2014)
Principal diagnosis: Incomplete cord syndrome of cervical spinal cord (S14.13) & functional spinal cord injury C4 (S14.74)
Comorbidities: None
Risk factors: Smoking

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
31-May-02	**7-Jul-03**			**S14.13 & S14.74**
28-Feb-05	17-Jul-05	2 years	2	Mechanical compression of urinary (indwelling) catheter (1) & UTI (1)
09-Mar-07	09-Mar-07	4 years	1	Mechanical compression of urinary (indwelling) catheter & UTI
27-Dec-07	30-Jun-08	5 years	4	Mechanical compression of urinary (indwelling) catheter (3), pressure ulcer (1) & UTI (1)
28-Sep-08	21-Jul-09	6 years	3	Pressure ulcer (3), prostatitis (2), UTI (1)
07-Sep-09	24-Jul-10	7 years	4	Autonomic dysreflexia (1), bowel complications (1), pressure ulcer (1) & UTI (4)
03-Aug-10	05-Jul-12	8 years	5	Abdominal pain (3), bowel complication (1) & UTI (5)
31-Oct-12	31-Oct-12	9 years	1	UTI
22-Nov-12	23-Mar-14	10 years	6	Abdominal pain (3), bowel complication (1), pressure ulcer (1) & UTI (5)

Case 13

A 27-year-old female smoker, diagnosed with complete lesion of cervical spinal cord (S14.11) and functional cervical injury C6, (S14.76) with a pre-existing mental disorder. However, she developed multiple myeloma in the third-year post-injury. After this diagnosis she was admitted 23 times for this condition, and once with UTI over a 4-year period.

24 readmissions – 27-year-old female
Admission Period: (Jan 2010 – April, 2014)
Principal diagnosis: Complete lesion of cervical spinal cord (S14.11) & functional cervical injury C6 (S14.76)
Comorbidities: Mental disorder (anxiety disorder)
Risk factors: Smoking

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
5-Jan-10	15-Jan-10			**S14.11 & S14.76**
05-Feb-10	05-Feb-10	1 month	1	Fitting and adjustment of urinary device
28-Apr-12	27-Dec-12	3 years	8	UTI (1), Multiple Myeloma (7), dysuria (painful or difficult urination)
29-Jan-13	18-Feb-14	4 years	12	Multiple myeloma (12)
18-Mar-14	15-Apr-14	5 years	3	Multiple myeloma (3), constipation (1), nausea vomiting (2), flatulence and related conditions (1)

Case 14

A 60-year-old male, with conus medullaris (S34.1) and functional spinal cord injury C2 (S14.72) injury with preexisting condition of hypotension. He was admitted 9 times with cellulitis in the 6 years post-discharge from the initial injury. He developed rectal cancer in the 8th year and then had frequent readmissions for treatment of cancer in subsequent years.

23 readmissions – 60-year-old male
Admission Period: (April 2000 to May 2014)
Principal diagnosis: Conus medullaris (S34.1) and functional spinal cord injury, C2 (S14.72)
Comorbidities: Hypotension
Risk factors: None recorded

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
10-Apr-00	**28-Jul-00**			**S34.1**
12-Oct-00	12-Oct-00	3 months	1	Cellulitis (1)
26-Dec-00	26-Dec-00	6 months	1	Cellulitis (1)
26-Nov-01	22-May-02	2 years	2	Cellulitis (2)
27-Aug-03	27-Aug-03	4 years	1	Cellulitis (1)
07-May-06	24-Jun-06	6 years	3	Abdominal pain (1), bowel complications cellulitis, constipation (2) and cellulitis (1)
21-Dec-07	21-Dec-07	8 years	1	Bowel complications (1), Cancer (rectum)
05-Nov-10	02-Mar-11	11 years	4	Cancer of rectum (4), pressure ulcer (1)
27-Jan-12	23-Apr-12	12 years	4	Cancer rectum (4), pressure ulcer (1)
14-Aug-12	12-Dec-12	13 years	3	Cancer rectum (3), pressure ulcer (1)
16-Sep-13	06-May-14	14 years	3	Cancer rectum (3), pressure ulcer (1)

Case 15

A 19-year-old female with conus medullaris and L1 injury was readmitted 23 times over a period of 10 years. She had a long hospital length of stay (208 days) at the time of the first injury. She was a smoker, was drug-dependent (including use of hypnotics) and suffered from depression. She was also a carrier of bacterial disease. She was admitted twice in the year first post discharge for UTI, and subsequently 21 times for mental disorders.

23 readmissions – 19-year-old female
Admission Period: (Feb 2001 - Feb 2010)
Principal diagnosis: Conus medullaris (S34.1) and functional spinal cord injury, L1 (S34.71)
Comorbidities: Mental disorder (depression), harmful use of hypnotics
Risk factors: Smoking, Hepatitis B carrier, harmful use of hypnotics

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
8-Feb-01	**4-Sep-01**			**S34.1 & S34.71**
20-Sep-01	20-Sep-01	1 month	1	Depression, UTI
25-Apr-02	26-Jul-02	1 year	10	Mental disorder; depression (10) & emotion-impulsive disorder (10) & UTI (1)
25-Sep-02	15-Dec-02	2 years	11	Mental disorder; depression (11) & emotion-impulsive disorder (11)
22-Feb-10	23-Feb-10	9 years	1	Mental disorder; depression (9) & emotion-impulsive disorder (9)

Case 16

A 27-year-old male was diagnosed with a complete lesion of the cervical cord at C4, and admitted 23 times over a period of 9 years. He had a history of hypotension and hypertension as well as suffering from a mental disorder (depression). Within three months of the initial discharge, he developed acute kidney failure. He was admitted 22 times for a range of SCI-related issues including autonomic dysreflexia, cellulitis, neurogenic bladder, pressure ulcer and UTI as shown below.

23 readmissions – 27-year-old, male
Admission Period: (March 2004 – Nov 2013)
Principal diagnosis: Complete lesion of cervical spinal cord (S14.11) & functional spinal cord injury, C4 (S14.74)
Comorbidities: Depression, hypertension & hypotension
Risk factors: None

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
4-Mar-04	**1-Jul-04**			**S14.11 & S14.74**
14-Sep-04	21-Sep-04	3 months	2	Acute kidney failure (1), pressure ulcer (1) & UTI (1)
27-May-05	27-May-05	1 year	1	Neurogenic bladder & UTI
31-Jul-06	01-Sep-06	3 years	2	UTI (1), fitting and adjustment of urinary device (1)
26-Jun-08	26-Jun-08	4 years	1	Fitting and adjustment of urinary device
16-Jul-08	22-Jul-08	5 years	6	Autonomic dysreflexia (1), neurogenic bladder (2) & UTI (4)
07-May-10	07-May-10	6 years	1	Autonomic dysreflexia, urinary retention and UTI
23-Oct-10	07-Dec-10	7 years	2	Autonomic dysreflexia (1), cellulitis (1), disorders of male genital regions (1) & urethral stricture (1)
20-Dec-11	21-Dec-11	8 years	2	Autonomic dysreflexia (1), other prosthetic device implanted (1) & UTI (1)
06-Sep-12	19-Dec-12	9 years	3	Cellulitis (2), other abnormal breathing difficulties, other follow up examination
02-Aug-13	15-Nov-13	10 years	3	Autonomic dysreflexia (3), hypothermia not associated with environment, tachycardia (1), mechanical complication of catheter (1)

Case 17

A 21-year-old male with incomplete cord syndrome (S14.13) and functional spinal cord injury at C5 (S14.75), was admitted 23 times over a period of 8 years. He smoked and had a history of hypotension. The main reasons for readmission were autonomic dysreflexia, pressure ulcer and UTI.

23 readmissions – 21-year-old male
Admission Period: (Jan 2004 – Dec 2012)
Principal diagnosis: Incomplete cord syndrome (S14.13) & functional spinal cord injury, C5 (S14.75)
Comorbidities: Hypotension
Risk factors: Smoking

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
26-Jan-04	**1-Jul-04**			**S14.13 & S14.75**
21-Aug-04	27-Aug-04	3 months	2	Constipation (1), pressure ulcer (1x), orchitis epididymitis with abscess (1), uropathy (1) & UTI (2)
31-Aug-04	27-Oct-04	6 months	3	Uropathy including hydronephritis (1), follow up rehabilitation (1) & UTI (1)
19-Mar-06	19-Jun-06	2 years	3	UTI (3)
31-Aug-06	01-Dec-06	3 years	3	Autonomic dysreflexia (1), pressure ulcer (3) & UTI (3),
10-Jul-08	14-Apr-09	4 years	5	Acute upper respiratory tract infection (1), autonomic dysreflexia (4), pressure ulcer (1) & UTI (4)
19-Jul-09	20-Feb-10	6 years	5	Attention to cystostomy (2), autonomic dysreflexia (4), unspecified convulsions (1) & UTI (4)
15-May-12	15-May-12	8 years	1	Autonomic dysreflexia (1), chronic tubulointerstitial nephritis (1), pressure ulcer (1) & UTI (1)
30-Dec-12	30-Dec-12	9 years	1	Tubulointerstitial nephritis & UTI

Case 18

A 45-year-old male diagnosed with C5 level injury, was readmitted 22 times over a period of 9.5 years. He had underlying type2 diabetes mellitus. Frequent reasons for readmission were sleep apnoea and UTI (8).

22 readmissions – 45-year-old male
Admission Period: (Dec 2004 – May 2014)
Principal diagnosis: Injury of spinal cord unspecified (S14.10) & functional spinal cord injury, C5 (S14.75)
Comorbidities: Type 2 diabetes mellitus
Risk factors: None recorded

First admission	Last discharge	Intervals	No of Admissions	Reasons for readmission
3-Dec-04	**13-Jan-05**			S14.10
15-Jan-05	7-Feb-05	1 month	3	Respiratory failure (1), Sleep apnoea (1) & UTI (2)
29-Mar-05	11-Apr-05	3 months	4	Sleep apnoea (3), fitting and adjustment of catheter (1), UTI (2)
8-Aug-05	22-Dec-05	1 year	2	Sleep apnoea (2), UTI (1)
11-Feb-06	11-Aug-06	2 years	3	Acute upper respiratory infection (1), malfunction of external stoma urinary tract (1) & UTI (1)
12-Feb-07	28-Oct-07	3 years	2	Head injury (1) & UTI (1)
05-Apr-08	17-Oct-08	4 years	2	Autonomic dysreflexia (1), dorsalgia (back pain) & UTI (1)
15-Jan-09	16-Jul-09	5 years	3	Dorsalgia (1), orthostatic hypotension (1), sleep apnoea (1) & venous thrombosis (1)
30-Mar-10	30-Mar-10	6 years	1	Bladder dysfunction
03-Mar-13	03-Mar-13	9 years	1	Respiratory complication & sleep apnoea
22-May-14	22-May-14	10 years	1	Sleep apnoea

Case 19

A 74-year-old female diagnosed with spinal cord injury unspecified (S14.10) was readmitted 21 times over 14 years. Her main reasons for readmission were heart-related issues such as chest pain and atrial fibrillation. She was also admitted due to SCI-related issues such as bowel complications, dysphagia, pressure ulcer, respiratory infections, urinary retention, and UTI over 14-year period.

21 readmissions –74-year-old female
Admission Period: (Jan 2000 – April 2014)
Principal diagnosis: Injury of cervical spinal cord, unspecified (S14.10)
Comorbidities: Type 2 diabetes mellitus
Risk factors: None recorded

First admission	Last discharge	Intervals	No of Admissions	Reasons for readmission
15-Jan-00	**15-Jan-00**			**S14.10**
02-Dec-00	02-Dec-00	1 year	1	Atrial fibrillation and flutter
07-Feb-01	07-Feb-01	2 years	1	Bowel complication
06-Feb-04	06-Feb-04	5 years	1	Atrial fibrillation and flutter
06-Apr-05	12-Jan-07	6 years	3	Abdominal pain (1), bowel complication (1), coagulation defects (1) & UTI (1)
23-Dec-07	31-Dec-07	8 years	2	Angina pectoris (1) atrial fibrillation and flutter (1), urinary retention (1) & UTI
09-Mar-08	05-Jan-09	9 years	6	Chest pain (1), dosalgia (2), malaise and fatigue (1), hypothermia (1)
01-Sep-09	01-Sep-09	10 years	1	Atrial fibrillation and flutter & diverticulitis
04-Jan-12	04-Jan-12	12 years	1	Chest pain unspecified & fracture of arm
28-Nov-13	05-Apr-14	14 years	5	Bowel complications (1), care involving use of rehabilitation (1), dysphagia (1), fracture of neck of humerus (1), pressure ulcer (1) & respiratory infection (1)

Case 20

A 51-year-old male with functional spinal cord injury at C6, a history of hypertension and a smoker, was readmitted 19 times over a period of 10 years, mainly for bladder and bowel problems and pressure ulcers.

21 readmissions – 51-year-old, male
Admission Period: (July 2002 – April 2013)
Principal diagnosis: Functional spinal cord injury, C6 (S14.76)
Comorbidities: Hypertension
Risk factors: Smoking

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
02-Jul-02	**02-Jul-02**			S14.76
24-Oct-05	24-May-06	4 years	2	Bowel complication (1), heart attack (1) & UTI (1)
28-Oct-08	22-Feb-09	7 years	3	Venous thrombosis, screen for cancer (family history), UTI (1)
10-Oct-09	25-May-10	8 years	7	Constipation (1), disorders of penis (1), infection due to device implanted (1), pathological fracture of pelvis (1), respiratory failure (1), soft tissue disorders & UTI (2)
26-Jul-10	24-Jun-11	9 years	4	Constipation (1), follow up with urinary catheter (1), pressure ulcer (2) & urethral strictures (1)
27-Jul-12	08-Apr-13	11 years	5	Follow up with urinary catheter (3), non-organic sleep disorder (1), pressure ulcer (1), urethral stricture (1)

Case 21

A 39-year-old male smoker, with incomplete cord syndrome of cervical spinal cord (S14.13) and functional spinal cord injury at C4, was readmitted 21 times over a period of 11 years. He had a pre-existing medical history of hypertension, hypotension and was a carrier of hepatitis. His main reasons for readmission were autonomic dysreflexia, constipation, respiratory infections, sleep apnoea and UTI.

21 readmissions –39-year-old male
Admission Period: (Jan 2008 – May 2014), LOS (46 days), ICU (46 hours)
Principal diagnosis: Incomplete cord syndrome of cervical spinal cord (S14.13) and functional spinal cord injury, C4 (S14.74)
Comorbidities: Hypertension and hypotension, hepatitis carrier
Risk factors: Smoking

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
27-Jan-08	**13-Mar-08**			**S14.13 & S14.74**
09-Apr-08	20-Aug-08	6 months	1	Constipation (1), fever unspecified (1), sleep apnoea (1) & venous thrombosis (1)
27-Sep-08	12-Feb-09	1 year	7	Abnormal head movement (1), Autonomic dysreflexia (2), constipation (1), flatulence of unknown origin, respiratory complication (1), sleep apnoea (1) & UTI (5)
06-Aug-10	08-Feb-11	3 years	2	Abdominal pain (1), autonomic dysreflexia (1), respiratory infection (1), Sleep apnoea (1)
09-Jan-12	13-Jan-12	4 years	2	Autonomic dysreflexia (1), constipation (1), sleep apnoea (1) & UTI (2)
25-Mar-12	30-Dec-12	5 years	5	Autonomic dysreflexia (1), constipation (1), respiratory complications (2), sleep apnoea (1) & UTI (2)
20-May-13	24-May-14	6 years	4	Acute upper respiratory tract infection (1), autonomic dysreflexia (1), bowel complications (1) & UTI (2)

Appendix 6D(b): Risk profile: Medium readmissions – (11 to 20 readmissions)

A 26-year-old male, with complete lesion of thoracic spinal cord (S24.11) & functional level thoracic T12 (S24.77) with no comorbidities and risk factors. The main reasons of readmission over six years and five months were cellulitis, neurogenic bladder, pressure ulcer, urethral stricture and urinary retention.
Three months (1x): Cellulitis, UTI
Two years (12x): Urethral stricture (12) and urinary retention (4)
Four years (2x): Urethral stricture (2)
Five years (1x): UTI
Six years (1x): Pneumonia
Seven years (1x): Cellulitis and pressure ulcer
Eight years (1x): Neurogenic bladder and UTI
Nine years (1x): Cellulitis, UTI, and urethral stricture.

20 readmissions –26-year-old male
Admission Period: (Jan, 2008 – May, 2014)
Principal diagnosis: Complete lesion of thoracic spinal cord (S24.11) & Functional level thoracic T12 (S24.77)
Comorbidities: None recorded
Risk factors: None recorded

First admission	Last discharge	Cumulative intervals	No of Admissions	Reasons for readmission
27-Jan-08	**13-Mar-08**			**S24.11 & S24.77**
09-Apr-08	20-Aug-08	6 months	1	Constipation (1), fever unspecified (1), Sleep apnoea (1) & venous thrombosis (1)
27-Sep-08	12-Feb-09	1 year	7	Abnormal head movement (1), Autonomic dysreflexia (2), constipation (1), flatulence of unknown origin, respiratory complication (1), sleep apnoea (1) & UTI (5)
06-Aug-10	08-Feb-11	3 years	2	Abdominal pain (1), autonomic dysreflexia (1), respiratory infection (1), Sleep apnoea (1)
09-Jan-12	13-Jan-12	4 years	2	Autonomic dysreflexia (1), constipation (1), sleep apnoea (1) & UTI (2)
25-Mar-12	30-Dec-12	5 years	5	Autonomic dysreflexia (1), constipation (1), respiratory complications (2), sleep apnoea (1) & UTI (2)
20-May-13	24-May-14	6 years	4	Acute upper respiratory tract infection (1), autonomic dysreflexia (1), bowel complications (1) & UTI (2)

19 Readmissions
36 years old male: admission period (Feb, 2000 – July, 2011). LOS (0), ICU (0)
Principal diagnosis: Other injury of lumbar spinal cord (conus medullaris) (S34.1)
Comorbidities: Personal history of degenerative nerve system
Risk factors; smoking, alcohol dependent
2 years (2x): degenerative nerve system
3 years (2x): Orthopaedic follow up
4 years (2x): Orthopaedic follow up
5 years (4x): Pulmonary embolism (1), bowel complications, headache (1), fracture of hand and wrist (1)
6 years (6x): Constipation (4), pulmonary embolism (2), Speech disturbances (1), hematemesis (vomiting blood), visual disturbances (1)
7 years (1x): Sleep apnoea, visual disturbances
8 years (1x): Complication of procedure
11 years (1x): Complication of procedure

18 Readmissions
24 years old male, admission (Jan, 2007 – May, 2013). LOS (27 days), ICU (254 hours)
Principal diagnosis: Complete lesion of spinal cord (S14.11) and functional spinal cord injury, C5 (S14.75)
Comorbidities: Mental disorder (depression)
Risk factor: Smoking, mental and behavioral change due to harmful use of tobacco
Three months (1x): Neurogenic bladder
Six months (1x): Sprain and strain of shoulder joint
One year (1x): Neurogenic bladder
Two years (1x): Pressure ulcer, Burns (< 10 of surface body), abnormal weight loss
Three years (3x): haematuria – unspecified (1), cystitis (1), UTI (1), acute tonsillitis (1)
Four years (1x): UTI & abdominal pain
Six years (6x): UTI (6), cerumen (built up of earwax) (1), infection due to urinary prosthetics (2), cystostomy status (1)
Seven years (2x): UTI (2), Rash and other skin eruption (1), cramp and spasm (1)
Eight years (2x): UTI (1), Neurogenic bladder (1)

17 Readmissions (3 patients):
Patient 17A:
22 years old male; admission period (May, 2005 – Dec, 2013). LOS (65), ICU (327 hours).
Principal diagnosis: Complete lesion of spinal cord (S14.11) and functional spinal cord injury, C5 (S14.75)
Comorbidities: hypertension
Risk factors: alcohol, smoking
One month (2x): UTI (1), sleep apnoea (1)
Two years (3x): UTI (2), Orchitis & epididymitis (1)
Five years (2x): urinary calculi (1) and sleep apnoea (1), chronic respiratory failure (1)
Six years (2x): UTI (1), mechanical complication with urinary catheter (1), infection from the urinary catheter (1)
Seven years (3x): UTI (2), constipation (1), fever of unknown origin (1), open wound of lower back and pelvis (1)
Eight years (4x): autonomic dysreflexia (1), abdominal pain (1), Sleep apnoea (1), UTI (1), respiratory complication (1)
Nine years (2x): abdominal pain (1), UTI (1)

Patient 17B:
20 years old male: admission period (Aug, 2003 – Dec, 2012). LOS (360), ICU (358 hours)
Principal diagnosis Complete lesion of thoracic spinal cord ($24.11)
Comorbidities: None recorded
Risk factors: None recorded
2 years (1x): Neurogenic bladder and UTI
5 years (1x): Neurogenic bladder and UTI
7 years (2x): Neurogenic bladder (1) and urinary retention (1), UTI (1), urinary calculi (1)
8 years (6x): Urinary retention (3), neurogenic bladder (1), urinary calculi (2), fitting and adjustment of urinary device (1)
10 years (3x): cystitis (1), neurogenic bladder (1), pressure ulcer (1), UTI (1), orchitis & epididymitis (1)
11 years (1x): Neurogenic bladder
12 years (2x): Neurogenic bladder (2)
13 years (1x): Male infertility

Patient C:
56 years old female: admission period (May, 2002 – July 2013). LOS (161 days), ICU (1,589 hours-66.2 days)
Principal diagnosis: Complete lesion of spinal cord (S14.11) and functional spinal cord injury, C5 (S14.75)
Comorbidities: Type2 DM
Risk factors: None recorded
One year (2x): sleep apnoea, cellulitis, infection following procedure, respiratory complications (2)
Two years (1x): sleep apnoea, cellulitis, infection following procedure
Three years (4x): sleep apnoea (1), cellulitis (1), infection following procedure (1), somnolence (1), oedema (1)
Four years (3x): Sleep apnoea (3), UTI (1)
Five years (2x): Sleep apnoea (2)
Six years (2x): Sleep apnoea (1), cellulitis (1), other complications of prosthetics implanted device
Seven years (1x): Breathing difficulties
Ten years (1x): Sleep apnoea

16 Readmission (9 patients):
Patient 16A:
72 years old male: admission period (Mar, 2006 – July, 2011). LOS (42 days), ICU (119 hours)
Principal diagnosis: Complete lesion of spinal cord (S14.11) and functional spinal cord injury, C5 (S14.75)
Comorbidities: Type2-DM, Hypothyroid
Risk factor: Alcohol dependence
Three months (2x): Chronic kidney disease (1), respiratory complication (1), heart failure (1), fitting and adjustment of urinary device
Six month (1x): fitting and adjustment of urinary device
One year (4x): Chronic kidney disease (4), cystitis (1), UTI (3), pressure ulcer (1), dosalgia (3), infection from urinary device
Two years (3x): Constipation (1), respiratory complication (1), UTI (1), mechanical complication with urinary catheter (1)

Patients 16B:
67 years old male: admission period (Oct, 2006 – Nov, 2012) LOS (24 days), ICU (49 hours)

Principal diagnosis: Central cord syndrome (S14.12) and functional spinal cord injury, C7 (S14.77)
Comorbidities: Hypotension
Risk factor: alcohol dependent, tobacco
One year (3x): UTI (1), urinary retention (1), rheumatism (1), hydrocoele unspecified (1)
Two years (5x): pneumonia (1), sleep apnoea (1), UTI (1), flexion deformity, cramp & spasm (1)
Three years (3x): sleep apnoea (2), flexion deformity (1)
Four years: (2x): sleep apnoea (1), flexion deformity (1)
Five years (3x): sleep apnoea (1), hemorrhoids (2)

Patients 16C:
33 years old male: admission period (Oct, 2005 – Jan, 2013) LOS (21), ICU (0)
Principal diagnosis: Central cord syndrome (S14.12) and functional spinal cord injury, C5 (S14.75)
Comorbidities: None recorded
Risk factor: None recorded
3 months (3x): Fever unknown (3), pressure ulcer (2)
1 year (1x): respiratory infection (1), UTI (1), Hydrocoele unspecified (1)
2 years (1x): Urinary incontinence, infection due to urinary device
3 years (1x): sleep apnoea, acute lower respiratory infection
4 years (3x): fever (1), urinary incontinence (2), mechanical complications with urinary catheter (1)
5 years (3x): acute lower respiratory infection (1), sleep apnoea (2), constipation (1)
7 years (1x): Urethral complication (1), mechanical complications with urinary catheter (1)
8 years (3x): constipation (2), urinary retention (1)

Patients 16D:
41 years old male, readmission period (Sept, 2009 – May, 2014). LOS (68 days), ICU (407 hours)
Principal diagnosis: complete lesion of cervical spinal cord (S14.11) & functional spinal cord injury, C4 (S14.74) and
Comorbidities: Type 2 DM & hypotension
Risk factors: smoking
One month (1x): Care involving rehabilitation (1), Fever of unknown origin (1), other mononeuropathies (1), pneumonia
Three months (1x): Fever of unknown origin
Six months (3x): acute respiratory failure (1), autonomic dysreflexia (1), mononeuropathies (1)
One year (3x): respiratory complication (3), UTI (3), pressure ulcer (1), urinary calculi (1)
Two years (2x): autonomic dysreflexia (2), pressure ulcer (1), pneumonia (1)
Three years (2x): autonomic dysreflexia (1), pressure ulcer (1), sleep apnoea (1), constipation (1), UTI (1)
Four years (1x): cellulitis
Five years (1x): Internal hemorrhoids without complication
Six years (2x): Pressure ulcer (2), iron deficiency (1), gastritis (1), bowel complications (1), pneumonia (1)

Patients 16E:
45 years old female, readmission period (July, 2004 – May, 2014) LOS (0), ICU (0)
Principal diagnosis: central cord syndrome (S14.12) & functional spinal cord injury unspecific (S14.70)
Comorbidities: Cancer of breast
Risk factor; None recorded
One month (2x): fibrous dysplasia (1), pharmacotherapy (1)
3 months (1x): fibrous dysplasia (1), pharmacotherapy (1)

One year (6x): fibrous dysplasia (6), pharmacotherapy (6), secondary neoplasia (6)
Two years (1x): fibrous dysplasia (1), pharmacotherapy (1)
Three years (1x): fibrous dysplasia (1), pharmacotherapy (1)
Six years (2x): fibrous dysplasia (2), pharmacotherapy (2)
Eight year (2x): fibrous dysplasia (2), pharmacotherapy (2), follow up care plastic surgery thoracic (1)
Ten years (1x): fibrous dysplasia (1), pharmacotherapy (1), follow up care plastic surgery thoracic (1)

Patients 16F:
85 years old male. Admission period (Jan, 2007 – Jan, 2012). LOS (1 day) ICU (0)
Principal diagnosis: central cord syndrome (S14.12) & functional spinal cord injury C5 (S14.75)
Comorbidities: Type2 DM, hypotension
Risk factor: none recorded
Six months (1x): Angina pectoris (1)
One year (2x): Spondylopathies (1) & Hernia (1)
Two years (2): chest pain (2)
Three years (7): chest pain (2), bowel complication (2), head wound (1), dysphagia (1), malaise & fatigue (1)
Four years (3): dysphagia (1), Neurogenic bladder (1), injury of abdomen and back (1)
Five years (1): Pressure ulcer, respiratory infection and constipation

Patients 16G:
45 years old male: admission period (April, 2002 – Jan, 2013) LOS (0), ICU (0)
Principal diagnosis: Central cord syndrome (S14.12) and functional spinal cord injury, cervical level unspecified (S14.70)
Comorbidities: Type2 – DM, mental disorder
Risk factor: Drug dependent (opium)
One month (4x): spondylosis (4), abnormal gait and mobility (1)
Three months (1x): abnormal gait and mobility (1)
1 year (1x): Head injuries – sub arachnoid hemorrhage, seizure
2 years (3x): Multiple injuries to shoulder and arm (1), instability of joint (1), mental disorder (depression) (3)
4 years (1x): Spondylopathies
5 years (2x): care involving rehabilitation (2), syncope (1)
6 years (2x): syncope (1), other unspecified convulsion (1)
11 years (3x): Constipation (1), pressure ulcer (1), sleep apnoea (1), joint disorder (1)

Patients 16H:
33 years old male: admission period (June, 2006 – Oct, 2012) LOS (9 days) ICU (0)
Principal diagnosis: Functional spinal cord injury C6 (S14.76) & complete lesion of cervical spinal cord (S14.11)
Comorbidities: Mental disorder (depression)
Risk factor: Hypotension
One month (2x): Nausea and vomiting (1), care involving use of rehabilitation
Three months (1x): constipation & venous thrombosis
One year (3x): Urinary incontinence, fitting and adjustment of urinary device
Two years (2x): Urinary incontinence (2)
Three years (4x): UTI (1), cellulitis (2), anaemia (1), coagulation problem (1), myositis (1)
Four years (2x): Myositis (inflammation of muscle)
Five years (1x): signs and symptoms involving urinary system, problem with urinary catheter

Six years (1x): signs and symptoms involving urinary system, problem with urinary catheter

Patients 16I:
21 years old male: admission period (Jan, 2001 – Aug, 2013) LOS (437 days) ICU (710 hours)
Principal diagnosis: Complete lesion of cervical spinal cord (S14.11) & Functional spinal cord injury, C5 (S14.75)
Comorbidity: Smoking
Risk factor: Hypotension
3months (1x): pneumonia, pressure ulcer, skin rash eruption
6 months (1x): respiratory complication (2), pressure ulcer (2), sleep apnoea (1)
Four years (2x): sleep apnoea (1), pressure ulcer (1), acute lower respiratory complication (2), gastrointestinal hemorrhage
Five years (2x): sleep apnoea (2), acute lower respiratory complication, gastrointestinal hemorrhage (1), pressure ulcer (1)
Six years (4x): Respiratory complications (2), UTI (1), sleep apnoea (1), other complication procedure (1)
Seven years (1x): chronic gingivitis (swollen gums) (1), in growing nail
Eight years (1x): chronic gingivitis
Nine years (1x): constipation and respiratory infection
Ten years (1x): Internal hemorrhoids
Eleven years (1x): respiratory complications, constipation
Twelve years (1x): Sleep apnoea, respiratory infection, pressure ulcer and UTI

15 Readmission (3 patients):
Patient 15A:
28 years old male: admission period (May, 2001 – July, 2012) LOS (236 days), ICU (208hours)
Principal diagnosis: Other incomplete cord syndrome of cervical spinal cord (S14.13) & functional spinal cord injury, C6 (S14.76)
Comorbidity: None recorded
Risk factor: None recorded
Two years (1x): respiratory disease
Three years (7x): sign and symptoms of nervous system (1) burns (less than 10 body total body mass) (1), self-harm (5x), cystostomy (1)
Five years (2x): self-harm (2x)
Six years (1x): self-harm
Nine years (1x): self-harm
Ten years (2x): self-harm (2)
Eleven years (1x): self-harm

Patient 15B:
76 years old male: admission period (March, 2008 – Oct, 2014) LOS (13 days) ICU (0)
Principal diagnosis: Complete lesion of thoracic spinal cord (S24.11) & functional level spinal cord injury T10/T11
Comorbidity: Hypertension, type2 DM
Risk factor: None recorded
Six months (1x): Urinary incontinence
One year (6x): fitting and adjustment of urinary device (1), heart attack (1), Acute kidney failure (1), cellulitis (1), fracture of femur (1), adjustment and management of implanted device (2)
Three years (1): acute kidney failure and cellulitis
Five years (2x): acute kidney failure (1), cellulitis (1) and superficial injury of shoulder and arm (1)

Six years (4x): fracture of lower leg (1), cellulitis (3), chronic kidney failure (3)
Seven years (1x): cellulitis (2) and chronic kidney failure (2)

Patient 15C:
78 years old male: admission period (Feb, 2000 – April, 2003) LOS (117) ICU (175 hours)
Principal diagnosis: Conus medullaris (S34.1) & functional spinal cord injury, lumbar level unspecified (S34.70)
Comorbidity: Mental disorder (depression & mood disorder)
Risk factor: None recorded
Six months (1x): Chronic kidney disease, dialysis
One year (1x): Chronic kidney disease, Other cardio vascular prosthetics implanted
Two years (2x): Chronic kidney disease, Other cardio vascular prosthetics implanted, Rash eruption
Three years (11x): Urinary continence (1), chronic kidney disease (10), dialysis (10), cellulitis (1x), atrial fibrillation and flutter (1)

14 Readmission (7 patients):
Patient 14A:
54 years old male: admission period (July, 2011 – Sept, 2013). LOS (89 days), ICU (358 hours)
Principal diagnosis: Complete lesion of cervical spinal cord (S14.11) & Functional spinal cord injury, C4 (S14.74).
Comorbidity: Mental disorder (depression)
Risk factor: None recorded
One month (3x): Respiratory complications (2), sleep apnoea (1) and urinary retention
Six months (6x): Respiratory complications (3), sleep apnoea (1) and UTI (1)
One year (1x): Sleep apnoea and respiratory complication
Two years (4x): Sleep apnoea (3), respiratory complication (4) and UTI (1)

Patient 14 B:
72 years old male: admission period (Nov, 2010 – May, 2014). LOS (15 days), ICU (19 hours)
Principal diagnosis: Central cord syndrome (S14.12) & Functional spinal cord injury, C5 (S14.75).
Comorbidity: Mental disorder (depression), cancer of blood (follicular lymphoma)
Risk factor: Smoking
One month (3x): Constipation (2)
Three years (9x): Pharmacotherapy session for cancer (9), disc stenosis (9)
Four years (2x): Pharmacotherapy session for cancer (2), disc stenosis (2)

Patient 14 C:
19 years old male: admission period (July, 2004 – June, 2013). LOS (30 days), ICU (127 hours)
Principal diagnosis: Complete lesion of cervical spinal cord (S14.11) & Functional spinal cord injury, C5 (S14.75).
Comorbidity: Mental disorder (depression)
Risk factor: None recorded
One month (2x): Pressure ulcer (1), neurogenic bladder (1)
Six months (3x): Pressure ulcer (2), gastric ulcer (2) and UTI (1)
One year (1x): Pressure ulcer (1)
Six years (4x): Respiratory complication (3), pressure ulcer (2), abdominal pain (1)
Eight years (3x): Pressure ulcer (3x), UTI (1),
Nine years (1x): chronic gastritis

Patient 14 D:

36 years old male: admission period (Aug, 2003 – Aug, 2013). LOS (46 days), ICU (22 hours)
Principal diagnosis: other incomplete cord syndrome of spinal cord (S14.13) & Functional spinal cord injury, C3 (S14.73).
Comorbidity: Mental disorder (depression)
Risk factor: smoking
One year (1x): UTI
Three years (3x): Sleep apnoea (1), spondylopathies (2)
Fours (2x): spondylopathies (2)
Five years (1x): Infection following procedure
Seven years (1x): spondylopathies
Nine years (3x): Polyneuropathies, constipation (1), spondylopathies (1)
Ten years (3x): spondylopathies (2) and pressure ulcer (1)

Patient 14 E:
21 years old male: admission period (Aug, 2005 – June, 2010). LOS (11 days), ICU (98 hours)
Principal diagnosis: Functional spinal cord injury, T10/T11 (S24.76)
Comorbidity: Mental disorder (depression)
Risk factor: alcohol, smoking
Six months (11x): Orchitis epididymitis without abscess (7), fever unknown (4), cystitis (1), uropathy (1)
Two years (2x): Uropathy (1), fever (1), disorders of meninges (1)
Five years (1): UTI & pressure ulcer

Patient 14 F:
17 years old male: admission period (Jan, 2000 – Jan, 2014). LOS (99 days), ICU (0)
Principal diagnosis: Complete lesion of thoracic spinal cord (S24.11)
Comorbidity: None recorded
Risk factor: smoking
Six months (1x): Pneumonia unspecified
Two years (1x): Pneumonia unspecified
Three years (2x): Pneumonia unspecified (2)
Five years (2x): Pneumonia unspecified, injury of neck unspecified (1)
Eight years (1x): Urinary calculi
Nine years (1x): Urinary calculi
Ten years (1x): Cystitis and neurogenic bladder
Eleven years (2x): Cystitis (2) and neurogenic bladder (2)
Twelve years (2x): Neurogenic bladder (2)
Fourteen years (1): Bowel complication, disease of tongue, pressure ulcer

Patient 14 G:
65 years old male: admission period (Sept, 2000 – Mar, 2009). LOS (99 days), ICU (0)
Principal diagnosis: Complete lesion of cervical cord (S14.11) & Functional spinal cord injury, C6 (S14.76).

Comorbidity: Carrier of infectious disease, hypotension, mental disorder (depression)
Risk factor: smoking
Six months (3x): Pressure ulcer (3)
Two years (3x): Pressure ulcer (2), syncope and collapse (1)
Three years (2x): Pressure ulcer (1), complications of procedure (1)
Four years (1x): Pressure ulcer, acute upper respiratory infection, Gastro-oesophagi reflux disease without esophagitis

Five years (1x): UTI, Infection from implanted urinary system
Six years (1x): Pressure ulcer
Seven years (1x): Neurogenic bladder
Eight years (2x): Pressure ulcer (2), UTI (1), acute lower respiratory infection

Readmission 13x: 4 patients: (0.5%)
Patient 13 A:
47 years old male: admission period (Jan, 2000 – Aug, 2013). LOS (0), ICU (0)
Principal diagnosis: Functional level thoracic injury T12 (S24.77)
Comorbidity: Carrier of infectious disease, hypotension, mental disorder (depression)
Risk factor: smoking
One year (1x): Cystitis and UTI
Two years (2x): Pressure ulcer (2) and UTI (2)
Three years (1x): Pressure ulcer and UTI
Four years (1x): Pressure ulcer and UTI
Seven years (1x): Pressure ulcer and UTI
Eight years (1x): Bowel complications, Pressure ulcer and UTI
Nine years (2x): Open wound (1), cellulitis and pressure ulcer (1)
Twelve years (2x): Cellulitis (2), UTI (1), chronic kidney disease, uropathy (1)
Thirteen years (1x): Cellulitis, pressure ulcer and chronic kidney disease
Fourteen years (1x): Cellulitis, pressure ulcer and chronic kidney disease

Patient 13 B:
30 years old male: admission period (Dec, 2007 – Sept, 2008). LOS (13 days), ICU (13)
Principal diagnosis: Complete lesion of thoracic spinal cord (S24.11) & Functional level of thoracic spinal cord injury, T12 (S24.77).
Comorbidity: None recorded
Risk factor: None recorded
Six months (4x): UTI (2), Nephritis (1), fractured sternum
One year (4x): UTI (1), pain in throat and chest (1), injury of thoracic aorta, thoracic pneumothorax (1)
Two years (2x): constipation (1), abnormal breathing
Four years (1x): Hypothermia not associated with environment
Five years (1x): UTI and autonomic dysreflexia
Six year (1x): Hemorrhoids

Patient 13 C:
20 years old male: admission period (May, 2004 – Nov, 2013). LOS (29 days), ICU (0)
Principal diagnosis: Other injury of lumbar spinal cord (conus medullaris) S34.1 & Functional spinal cord injury, L1 (S34.71).
Comorbidity: None recorded
Risk factor: None recorded
3 years (1x): infection due to cardio vascular implant device
5 years (1x): chronic kidney disease, urethral complications, anaemia
6 years (2x): Iron deficiency anaemia
8 years (4x): Neurogenic bladder (1), constipation (1), chronic kidney disease (1)
9 years (1x): Kidney transplant failure
10 years (3x): Kidney transplant failure
11 years (1x): Neurogenic bladder

Patient 13 D:
77 years old male: admission period (Nov, 2000 – Nov, 2006). LOS (1 days), ICU (0)
Principal diagnosis: Functional spinal cord injury, C5 (S14.75).
Comorbidity: Hypotension and hypertension
Risk factor: smoking
Six months (3x): sleep apnoea (1), UTI (2), respiratory infection
One year (1x): Respiratory infection, UTI and poly of stomach and duodenum
Two years (4x): mechanical complication of urinary catheter (2), respiratory infection (2), UTI (1)
Three years (2x): complication with prosthetics (2)
Four years (1x): cystitis and complication with urinary catheter
Six years (1x): Disorders of muscle
Seven years (1x): Respiratory infection

Readmission 12x: 8 patients (1.0 %)
Patient 12A:
44 years old male: admission period (July, 2004 – Feb, 2009). LOS (67 days), ICU (0)
Principal diagnosis: Central cord syndrome (S14.12) & functional spinal cord injury unspecified (S14.70
Comorbidity: Hypertension & Hypotension
Risk factor: Smoking
Three months (2x): UTI & Bone disorder
Six months (4x): UTI (2), dental problem (1), joint disorder (1)
One year (1x): disorders of autonomic nervous system
Three years (3x): constipation (1), fracture femur (1), UTI (1)
Four years (1): gastric ulcer
Five years (1): UTI

Patient 12B:
34 years old male: admission period (July, 2008 – June, 2014) LOS (72 days), ICU (0)
Principal diagnosis: complete lesion of thoracic spinal cord (S24.11) & functional level thoracic spinal cord injury T4/T5 (S24.73)
Comorbidity: Hypotension
Risk factor: None recorded
Three months (3x): sleep apnoea (3), pneumonia (2), pressure ulcer (1), thoracic root disorder (1)
One year (3x): thoracic root disorder (2), respiratory complication (2), UTI (1)
Two years (4x): thoracic root disorder (4), respiratory complication (4), constipation (4)
Six years (2x): thoracic root disorder (2), respiratory infection (2), acute kidney failure with tubular necrosis (1)

Patient 12 C:
31 years old male: admission period (June, 2003 – April, 2013) LOS (279 days), ICU (0)
Principal diagnosis: Functional level thoracic spinal cord injury T4/T5 (S24.73)
Comorbidity: Type2 – DM, mental disorder (depression)
Risk factor: Alcohol, smoking
Three years (4x): injury of urethra (1), other urethral complications (1), disorientation involving cognition and awareness (2)
Four years (1): Neurogenic bladder
Five years (5): UTI (1), disorders of brain (4)
Six years (1): urinary incontinence
Ten years (1): UTI and acute chronic failure

Patient 12 D:
78 years old male: admission period (March, 2000 – Feb, 2008) LOS (279 days), ICU (0)
Principal diagnosis: Central cord syndrome (S14.12)
Comorbidity: Mental disorder (depression)
Risk factor: Alcohol, hypertension
One year (1): cataract
Two years (1): Haemorrhage from respiratory passages
Three years (3): sleep apnoea (1), pressure ulcer (2), UTI (2)
Five years (1): pressure ulcer and UTI
Six years (1): sleep apnoea, neurogenic bladder, pressure ulcer, UTI, respiratory infection
Eight years (5x): sleep apnoea (1), UTI (3), urinary retention (1), atrial fibrillation and flutter (1)

Patient 12 E:
24 years old male: admission period (May, 2009 – Nov, 2013) LOS (32 days), ICU (113 hours)
Principal diagnosis: Other incomplete cord syndrome of cervical spinal cord (S14.13) & Functional spinal cord injury, C7 (S14.77)
Comorbidity: Mental disorder (depression) & hypotension
Risk factor: Smoking
Three months (3x): Pneumonia (1), UTI (2)
Six months (1x): calculus of lower urinary tract
2 years (1x): Joint disorders
3 years (4x): Acute upper respiratory tract infection, multiple & unspecified sites, sleep apnoea (1), pressure ulcer (1)
4 years (1x): UTI & pressure ulcer
5 years (1x): respiratory infection, Disorders tooth development & eruption
6 years (1x): acute lower respiratory infection

Patient 12 F:
68 years old male: admission period (May, 2009 – Nov, 2013) LOS (32 days), ICU (113 hours)
Principal diagnosis: Complete lesion of cervical spinal cord (S14.11) & Functional spinal cord injury, C5 (S14.75)
Comorbidity: Hypotension & hypertension
Risk factor: None recorded
One month (1x): pressure ulcer, UTI
Three months (1x): UTI
Six months (1x): Neurogenic bladder
Two years (2x): Neurogenic bladder (1), respiratory infection (1), chronic kidney disease (1), bowel complication (1)
Three years (4x): pressure ulcer (3), respiratory infection (1), sleep apnoea (2)
Five years (1x): haemorrhoids
Six years (1x): sleep apnoea, cellulitis and UTI
Seven years (1x): UTI & malaise and fatigue

Patient 12 G:
20 years old male: admission period (Oct, 2011 – Dec, 2014) LOS (217 days), ICU (0)
Principal diagnosis: Functional spinal cord injury, C4 (S14.74)
Comorbidity: Mental disorder (depression)
Risk factor: None recorded
One month (1x): Nail disorder, Follow-up care involving plastic surgery
Three months (2x): Nail disorder (1), Follow-up care involving plastic surgery (1), Other acquired deformity of head (1)

Six months (2x): Other acquired deformity of head (1), Tachycardia unspecified (1)
One year (1x): Other acquired deformity of head, Follow-up care involving plastic surgery
Two years (3x): Other acquired deformity of head (3), Follow-up care involving plastic surgery (3)
Three years (3x): Syncope and collapse (1), Other complications of procedures NEC (1), Failure & rejection other transplant organ tissue

Patient 12 H:
50 years old male: admission period (Feb, 2007 – Mar, 2014) LOS (62 days), ICU (0)
Principal diagnosis: Complete lesion of cervical spinal cord (S14.11) & functional spinal cord injury, C4 (S14.74)
Comorbidity: Type2 DM, hypotension
Risk factor: Smoking
One month (2x): pressure ulcer (1), pneumonia (1) & UTI (1)
Six months (3x): Neurogenic bladder (1), UTI (2) & pneumonia (1)
4 years (1x): pressure ulcer
5 years (2x): hemorrhoids (2)
6 years (1x): hemorrhoids
7 years (3x): respiratory infection (2), pressure ulcer (3), UTI (2), heart failure (1)

Readmission 11x: 11 patients (1.4 %)

Patient 11 - 1
57 years old male: admission period (Feb, 2000 – Mar, 2012) LOS (0), ICU (0)
Principal diagnosis: Functional spinal cord injury, C4 (S14.74)
Comorbidity: Hypertension
Risk factor: Smoking
No admission till 4th year post discharge
Four years (4x): nerve roots plexus disorder (1), cervical disc disorder with myelopathy (1), spinal stenosis cervical region (1), operation wound (1), intervertebral disc disease (1)
Seven years (2x): atherosclerotic heart disease (1), respiratory disorder (1), fever (1), constipation (1).
Eight years (1x): cervical disc disorder with myelopathy
Ten years (1x): derangement of knee
Eleven years (1x): superficial injury of head
Twelve years (2x): constipation (2), foreign body in respiratory part (1)

Patient 11 - 2
34 years old male: admission period (Sept, 2001 – Sept, 2011) LOS (0), ICU (0)
Principal diagnosis: Other injury of lumbar spinal cord [Conus medullaris]
Comorbidity: Mental disorder (depression), dementia
Risk factor: None
No admission till 3rd year.
Three years (2x): bowel complication (1), follow up after reaction to surgery (1)
Five years (1x): open head injury
Eight years (3x): bowel complication (2), pressure ulcer (1), hemorrhoids (1), fracture of femur (1)
Nine years (1x): Urinary retention
Ten years (1x): Intracranial injury
Eleven years (3x): Atrophy of skin disorder (1), cancer of trachea (1), osteoporosis (1)

Patient 11 - 3
49 years old male: admission period (Oct, 2009 – Aug, 2013) LOS (0), ICU (0)
Principal diagnosis: Complete lesion of thoracic spinal cord (S24.11)
Comorbidity: Mental disorder (depression)
Risk factor: Delirium unspecified, hypertension and hypotension
Three months (2x): sleep apnoea, respiratory infection, bowel complication and acute kidney failure (2)
One year (4x): acute kidney failure (1), pressure ulcer (3x), UTI (2), sleep apnoea (1)
Two years (1x): bowel complications & other soft tissue disorder
Three years (4x): Acute post haemorrhagic anaemia (1), constipation (1), bowel complications (4), pressure ulcer (3), anaemia (1)

Patient 11 - 4
49 years old male: admission period (Oct, 2009 – Aug, 2013) LOS (0), ICU (0)
Principal diagnosis: Complete lesion of cervical spinal cord (S14.11) & functional spinal cord injury, C5 (S14.75)
Comorbidity: Mental disorder (depression)
Risk factor: Delirium unspecified, hypertension and hypotension
One month (3x): respiratory complications (1), constipation (1), pressure ulcer and UTI
Three months (1x): Pressure ulcer
Six months (1x): Cystitis
One-year (4x): Mech comp urinary (indwelling) catheter (2), pneumonia (1), pressure ulcer (1)
Two years (3x): Pneumonia (1), autonomic dysreflexia (1), mech comp urinary (indwelling) catheter (1)

Patient 11 - 5
31 years old male: admission period (Feb, 2004 – Mar, 2012) LOS (130 days), ICU (259 hours)
Principal diagnosis: Complete lesion of cervical spinal cord (S14.11) & functional spinal cord injury, T2/T3 (S24.72)
Comorbidity: None
Risk factor: None
One year (1x): Neurogenic bladder, UTI
Two years (2x): Fever of unknown origin (1), UTI (1)
Three years (2x): UTI (2)
Five years (2x): Neurogenic bladder (1), fitting and adjustment of urinary device (1)
Six years (3x): Fitting and adjustment of urinary device (2), Autonomic dysreflexia (1), Urethral stricture unspecified (1)
Eight years (1x): Autonomic dysreflexia, UTI & Orchitis epididymitis without abscess

Patient 11 - 6
17 years old male: admission period (April, 2008 – Nov, 2013) LOS (0), ICU (0)
Principal diagnosis: Complete lesion of cervical spinal cord (S14.11)
Comorbidity: None
Risk factor: None
One month (1x): Neurogenic bladder
Three months (4x): Neurogenic bladder (1), UTI (1) & injury of urethra (1), Follow-up exam after surgery (3)
Six months (1x): Follow-up exam after surgery
One year (2x): Neurogenic bladder and care involving use of rehab procedure
Six years (3x): Neurogenic bladder (1), UTI (1), attention to cystostomy (1)

Patient 11 - 7
27 years old male: admission period (March, 2002 – May, 2014) LOS (111), ICU (461 hours)
Principal diagnosis: Injury of spinal cord, unspecified (S14.10) & functional spinal cord injury, C5 (S14.75)
Comorbidity: Hypertension
Risk factor: Alcohol dependent, smoking
One month (1x): Disorders autonomic nervous system
Two years (5x): Disorders autonomic nervous system (4), urinary retention (1), neurogenic bladder

(1), complication of prosthetics device implant graft (1)
Three years (2x): Fitting and adjustment of urinary device (1), UTI (1) & agranulocytosis (1)
Six years (2x): UTI (1), disorders autonomic nervous system (1) & complication of prosthetics device implant graft (1)
Twelve years (1x): Disorders autonomic nervous system, pneumonia and pressure ulcer

Patient 11 - 8
51 years old male: admission period (Dec, 2006 – April, 2014) LOS (8 days), ICU (0)
Principal diagnosis: Injury of spinal cord, unspecified (S14.10)
Comorbidity: Cancer of liver
Risk factor: Type 1 - DM
Three months (1x): Breathing difficulty
Six months (1x): Sleep apnoea
Three years (1x): Sleep apnoea
Four years (1x): Breathing difficulty
Five years (3x): Cancer of liver, osteoporosis (1), bowel complications (1), Oesophageal varices (1), paraphimosis (1)
Seven years (2x): Cancer of liver, osteoporosis, bowel complications
Eight years (2x): Special screen examination for special disorder (1), Pleural effusion (1)

Patient 11 - 9
29 years old male: admission period (Jan, 2005 – Sept, 2010) LOS (11 days), ICU (27 hours)
Principal diagnosis: Injury of spinal cord, unspecified (S14.10) & functional level of thoracic spinal cord injury, T1 (S24.71)
Comorbidity: None recorded
Risk factor: None recorded
Six months (1x): pneumonia, pressure ulcer & UTI
One year (5x): pressure ulcer (1), polyuria (1), UTI (3), cellulitis (1) & bursopathy unspecified
Two years (2x): neurogenic bladder (1), UTI (2)
Five years (1): Neurogenic bladder
Six years (2x): autonomic dysreflexia (1), dermatitis, uropathy (1), neurogenic bladder (1), fever (1), fitting and adjustment of urinary device

Patient 11 – 10
57 years old male: admission period (Oct, 2000 – June, 2013) LOS (273 days), ICU (551 hours)
Principal diagnosis: Incomplete cord syndrome of cervical spinal cord (S14.13) & functional level of cervical spinal cord injury, C6 (S14.76)
Comorbidity: None recorded
Risk factor: None recorded
Two years (2x): malaise & fatigue (1), sleep apnoea (1)

Three years (3x): constipation (1), UTI (2), neurogenic bladder (1), diverticulitis (1), other bowel complications
Six years (1x): UTI & urinary incontinence
Eight years (1x): UTI & urinary incontinence
Nine years (1x): headache & abnormal reflex

Patient 11 – 11
54 years old male: admission period (Feb, 2005 – May, 2011) LOS (37 days), ICU (551 hours)
Principal diagnosis: Incomplete cord syndrome of cervical spinal cord (S14.13) & functional level of cervical spinal cord injury, C4 (S14.74)
Comorbidity: Mental disorder, Hypertension, hypotension
Risk factor: smoking
Six months (3x): constipation (2), pressure ulcer (2), chronic kidney disease (2), shoulder lesion (1)
Two years (1x): coxa plana
Three years (1x): UTI
Four years (2x): Respiratory infections (3), disorders of synovium and tendon (1)
Five years (2x): disorder synovium & tendon (1), respiratory infection (1), cellulitis (1) and Infection due to prosthetics device implanted urinary system
Six years (1x): haemorrhoids
Seven year (1x): upper respiratory infection, pressure ulcer & pain in a joint shoulder region

Appendix 6D(c): Risk profile: Low readmissions (1 to 10 readmissions)

10x readmission Summary Table: (15 patients)
Total 15 patients were readmitted. Two females admitted in the age range of 16-30 (C5 injury) and 31-45 (C6) whilst 13 males were from all age ranges.

Age range	16-30		31-45		46-60	61-75	76+	Total patients
Sex	F	M	F	M	M	M	M	
Principal diagnosis								
Incomplete cord syndrome of cervical spinal cord (S14.13)							1	1
Functional spinal cord injury, C4 (S14.74)					1			1
Functional spinal cord injury, C5 (S14.75)	1	2				1		4
Functional spinal cord injury, C56(S14.76)			1				1	2
Complete lesion of thoracic spinal cord (S24.11)				1				1
Functional level of thoracic spinal cord injury T4/T5 (S24.73)				1	1			2
Functional level of thoracic spinal cord injury T8/T9 (S24.75)						2		2
Functional level of thoracic spinal cord injury T12 (S24.77)					1			1
Injury of lumbar spinal cord [conus medullaris] (S34.1)							1	1
Total	**1**	**2**	**1**	**2**	**3**	**3**	**3**	**15**

Principal diagnosis- admission separated by intervals										
Intervals	**S14.13**	**S14.74**	**S14.75**	**S14.76**	**S24.11**	**S24.73**	**S24.75**	**S24.77**	**S34.1**	**Total**
1month			2	1			1			4
3months		1	3	2		2			1	9
6months			4	2		2	1	1		10
1year	2	1	2	1		1	1		1	9
2years	1	1	3	1		1	1	1		9
3years		1	2			1	1		1	6
4years	1					1	1		1	4
5years			2					1		3
6years	1	1					1			4
7years	1	1			1		1	1		5
8years			1		1		1			3
9years					1					1
10years		1	1							2
11years					1			1		2

Total 4 patients were admitted after 1 month from being discharged. Principal diagnosis for those patients were S14.75 (2 patients), S14.76 (1 patient), S24.75 (1 patient).

Appendix 6E: Separation by intervals: reasons for readmission

SCI related secondary conditions	**1M**	**3M**	**6M**	**1Y**	**2Y**	**3Y**	**4Y**	**5Y**	**6Y**	**7Y**	**8Y**	**9Y**	**10Y**	**11Y**	**Total**
Uropathy	5			2	1		2								10
Other urethral complications	2	3			4			1			1				11
Venous thrombosis	0	6	3	1	3										13
Fracture	1	5	2	3	1	3						1			16
Pulmonary embolus	4	6	5	2	1										18
Urethral stricture	8	3	1	5	7	2		1	1	1	1				30
Fitting & adj of urinary device	0	21	7	2	2										32
Fever (unspecified)	14	12	5	4	1	1		1							38
Acute kidney failure	17	9	7	5	6		2	1							47
Cystitis	10	14	6	8	5	2	1	1							47
Care involving dialysis	37	6	1	1	1		1								47
Autonomic dysreflexia	18	6	12	7	6	1			2						52
Other orthopaedic follow-up care	28	13	4	2	4	2		1							54
Urinary calculi	13	14	9	6	5	3	3			1	1	1			56
Urinary incontinence & polyurea	10	18	12	11	4	1	2	1							59
Urinary retention	22	17	6	4	9	2	2		2		1				65
Cellulitis	18	15	7	15	6	6	3		1	1		1			73
Chronic kidney disease	61	21	10	15	8		4	0							119
Neurogenic bladder	35	34	14	30	13	7	3	2	1						139
Care inv use of rehab procedure	59	53	34	7	5	3		1			1		3		166
Sleep apnoea	52	40	24	26	17	3		2	1	**2**	**1**	1			169
Bowel complication	46	41	33	26	14	2	7	1	2	1				1	173
Respiratory complication	63	57	58	36	25	6	10	4	1			1		2	245
Mental disorders	109	92	58	55	29	17	7	3		3	2				375
Pressure area or ulcer	101	112	54	51	37	23	8	6	2	5	2	2		1	403
Urinary tract infection (UTI)	172	180	100	72	49	11	16	11	3	3	3	2	1		623

Appendix 6F: Details of readmissions at each time-point post-discharge

Appendix 6Fa: Total readmission at one-month

406 patients, 1,077 episodes, 905 SCI related ICD-10-AM codes		
Medical description	**Count**	**% Count**
Urinary tract infection	233	14.0
Pressure area or ulcer	148	8.9
Mental disorders	109	6.9
Sleep apnoea	52	4.0
Respiratory complications	65	3.9
Chronic kidney disease	65	3.9
Care inv use of rehab procedure	64	3.9
Other medical care	57	3.9
Care involving dialysis	46	2.8
Bowel complications	46	2.7
Neurogenic bladder	35	1.6
Retention of urine	22	1.5
Urinary incontinence & polyuria	21	1.3
Acute kidney failure	17	1.2
Cellulitis	18	1.1
Calculus of lower urinary tract	13	0.8
Fever of unspecified origin	13	0.8
Autonomic dysreflexia	12	0.7
Cystitis	10	0.7
Other disorders of bladder	9	0.6
Urethral stricture	8	0.5
Obstructive and reflux uropathy	5	0.3
Other orthopaedic follow-up care	6	0.3
Upper or lower fracture	4	0.3
Pulmonary embolism	4	0.3
Venus thrombosis	3	0.2
Prostatitis	3	0.2
Other urethral complications	2	0.1
Chronic pain	2	0.1
Other urethral complication	2	0.1

Appendix 6Fb: Total readmission at three months

Total: 430 patients, 818 episodes, 798 SCI related ICD-10-AM codes		
Medical description	**Count**	**% Count**
Urinary tract infection	180	14.0
Pressure area or ulcer	112	8.7
Mental disorders	92	13.0
Respiratory complications	57	4.4
Care inv use of rehab procedure	53	4.1
Bowel complications	41	3.2
Sleep apnoea	40	3.1
Neurogenic bladder	34	2.6
Chronic kidney disease	21	1.6
Fitting and adjustment of other devices	21	1.7
Urinary incontinence & polyuria	18	1.4
Retention of urine	17	1.4
Cellulitis	15	1.2
Urinary calculi	14	1.1
Cystitis	14	1.1
Orthopaedic follow-up care	13	1.1
Fever	12	0.9
Acute kidney failure	9	0.7
Autonomic dysreflexia	6	1.0
Pulmonary embolism	6	0.5
Venus thrombosis	6	0.5
Care involving dialysis	6	0.5
Upper or lower limb fracture	5	0.5
Urethral stricture	3	0.2
Other urethral complication	3	0.3
Heterotopic ossification	1	0.1

Appendix 6Fc: Total readmission at six months

Total 291 patients, 423 episodes, 472 SCI related ICD-10-AM codes		
Medical description	**Count**	**% Count**
Urinary tract infection	100	20.9
Respiratory complication	58	12.1
Mental disorders	58	12.1
Pressure area or ulcer	54	11.3
Care inv use of rehab procedure unspecific	34	7.1
Bowel complication	33	6.9
Sleep apnoea	24	5.0
Neurogenic bladder	14	2.9
Urinary incontinence & polyuria	12	2.5
Autonomic dysreflexia	12	2.5
Chronic kidney disease stage 1	10	2.1
Urinary calculi	9	1.9
Cellulitis	7	1.5
Acute kidney failure	7	1.5
Fitting and adjustment of urinary device	7	1.5
Urinary retention	6	1.3
Cystitis	6	1.3
Pulmonary embolus	5	1.0
Fever (unspecified)	5	1.0
Follow up care (orthopaedic)	4	0.8
Venus thrombosis	3	0.6
Cystitis	3	0.6
Fracture	2	0.4
Other disorders of bladder	2	0.4
Orthostatic hypotension	1	0.2
Urethral stricture	1	0.2
Extracorporeal dialysis	1	0.2

Appendix 6Fd: Total readmission at twelve months

Total: 233 patients; 397 episodes, 396 SCI related ICD-10-AM codes		
Medical description	**Count**	**% Count**
Urinary tract infection	72	10.4
Mental disorders	55	8.0
Pressure area or ulcer	51	7.5
Respiratory complication	36	5.3
Neurogenic bladder	30	4.4
Sleep apnoea	26	3.8
Bowel complication	26	3.8
Chronic kidney	15	2.2
Cellulitis	15	2.1
Urinary incontinence & polyuria	11	1.6
Cystitis	8	1.1
Autonomic dysreflexia	7	1.0
Other disorders of bladder	7	1.0
Urinary calculi	6	0.8
Acute kidney failure	5	0.7
Urethral stricture	5	0.7
Urinary retention	4	0.6
Fever (unspecified)	4	0.6
Pulmonary embolus	2	0.3
Fracture	3	0.3
Fitting and adjustment of urinary device	2	0.3
F/U care for orthopaedic fix	2	0.3
Uropathy including hydronephrosis	2	0.2
Extracorporeal dialysis	1	0.2
Venus thrombosis	1	0.1
Care inv use of rehab procedure unspecified	7	0.1

Appendix 6Fe: Total readmission at two years

Total: 165 patients, 245 episodes, 263 SCI related ICD-10-AM SCI codes		
SCI related secondary conditions	**Count**	**% Count**
Urinary tract infection	49	11.9
Pressure area or ulcer	37	9.0
Mental disorder	29	7.0
Respiratory complication	25	5.9
Sleep apnoea	17	4.1
Bowel complication	14	3.2
Neurogenic bladder	13	3.2
Retention of urine	9	2.2
Chronic kidney disease	8	1.9
Urethral stricture	7	1.7
Cellulitis	6	1.5
Acute kidney failure	6	1.5
Autonomic dysreflexia	6	1.4
Cystitis	5	1.2
Care inv use of rehab procedure	5	1.2
Calculus of kidney and ureter	5	1.2
Urethral complication	4	1.0
Orthopaedic follow-up care	4	1.0
Urinary incontinence and polyuria	4	0.8
Fitting and adjustment of other devices	2	0.5
Pulmonary embolism	1	0.2
Uropathy including hydronephrosis	1	0.2
Fever (unspecified)	1	0.2
Fracture of shoulder and upper arm	1	0.2
Care involving dialysis	1	0.2

Appendix 6Ff: Total readmission at three years

Total 93 patients, 111 episodes, 95 SCI related ICD-10-AM codes		
SCI related secondary conditions	**Count**	**% Count**
Pressure area or ulcer	23	12.6
Mental disorder	17	9.3
Urinary tract infection	11	6.0
Neurogenic bladder	7	3.8
Cellulitis	6	3.7
Respiratory complication	6	3.3
Sleep apnoea	3	1.8
Urinary calculi	3	1.6
Care inv use of rehab procedure	3	1.5
Fracture	3	1.5
Bowel complication	2	1.2
Urethral stricture	2	1.2
Cystitis	2	1.2
Orthopaedic follow-up care	2	1.2
Urinary retention	2	1.1
Other disorders of bladder	1	0.6
Autonomic dysreflexia	1	0.5
Urinary incontinence and polyuria	1	0.5
Fever (unspecified)	1	0.5

Appendix 6Fg: Total readmission at four years

Total: 60 patients, 64 episodes, 71 SCI related ICD-10-AM codes		
SCI related secondary conditions	**Count**	**% Count**
Urinary tract infections	16	13.3
Respiratory complication	10	8.3
Mental disorder	7	6.7
Decubitus ulcer and pressure area	8	6.7
Other disorders of bladder	4	3.5
Chronic kidney disease	4	3.2
Cellulitis	3	2.7
Neurogenic bladder	3	2.7
Urinary calculi	3	2.5
Urinary incontinence and polyuria	2	1.8
Uropathy including hydronephrosis	2	1.8
Urinary retention	2	1.8
Acute kidney failure	2	1.6
Cystitis	1	0.9
Care involving dialysis	1	0.9

Appendix 6Fh: Total readmission at five years

Total: 36 patients, 38 episodes, 37 SCI related ICD-10-AM codes		
SCI related secondary conditions	**Count**	**% Count**
Other disorders of urinary system	11	17.2
Pressure area or ulcer	6	9.4
Respiratory complication	4	6.3
Mental disorder	3	4.5
Neurogenic bladder	2	3.2
Urinary incontinence and polyuria	3	3.2
Sleep apnoea	2	3.1
Bowel complication	1	1.6
Acute kidney failure	1	1.6
Cystitis	1	1.6
Urethral stricture	1	1.6
Other urethral complication	1	1.6
Fever (unspecified)	1	1.6
Orthopaedic follow-up care	1	1.6
Care inv use of rehab procedure	1	1.6

Appendix 6Fi: Total readmission at six years

Total: 21 patients, 21 episodes, 16 SCI related ICD-10-AM codes		
SCI related secondary conditions	**Count**	**% Count**
Urinary tract infection	3	7.7
Mental disorder	2	5.1
Bowl complication	2	5.1
Pressure are or ulcer	2	5.1
Retention of urine	2	5.1
Sleep apnoea	1	2.6
Autonomic dysreflexia	1	2.6
Respiratory failure NEC	1	2.6
Cellulitis	1	2.6
Neuromuscular dysfunction of bladder NEC	1	2.6
Urethral stricture	1	2.6
Total	17	51.5

Appendix 6Fj: Total readmission at seven years

Total: 20 patients, 20 episodes, 17 SCI related ICD-10-AM codes		
SCI related secondary conditions	**Count**	**% Count**
Pressure area or ulcer	5	15.1
Mental disorder	3	9.1
Urinary tract infection	3	9.1
Sleep apnoea	2	6.1
Bowel complication	1	3.0
Cellulitis	1	3.0
Calculus of kidney and ureter	1	3.0
Cystitis	1	3.0
Total	17	51.5

Appendix 6Fk: Total readmission at eight years

Total: 10 patients, 10 episodes, 13 SCI related ICD-10-AM codes		
SCI related secondary conditions	**Count**	**% Count**
Mental disorder	2	11.8
Urinary tract infection	3	17.6
pressure area or ulcer	2	11.8
Retention of urine	1	5.9
Sleep apnoea	1	5.9
Calculus of lower urinary tract	1	5.9
Other disorders of urethra	1	5.9
Urethral stricture	1	5.9
Care inv use of rehab procedure	1	5.9
Total	13	76.5

Appendix 6Fl: Total readmission at nine years

Total: 10 patients, 10 episodes, 9 SCI related ICD-10-AM codes		
SCI related secondary conditions	**Count**	**% Count**
Urinary tract infections	2	14.2
Pressure area or ulcer	2	14.2
Fracture	1	7.1
Sleep apnoea	1	7.1
Calculus of kidney and ureter	1	7.1
Cellulitis	1	7.1
Respiratory complication	1	7.1
Total	9	64.1

Appendix 6Fm: Total readmission at ten years

Total: 4 patients, 4 episodes, 4 SCI related ICD-10-AM codes		
SCI related secondary conditions	**Count**	% Count
Urinary tract infection	1	0.25
Care involving rehabilitation	3	0.75
Total	4	100

Appendix 6Fn: Total readmission at eleven years

Total: 5 patients, 5 episodes, 4 SCI related ICD-10-AM codes		
SCI related secondary conditions	**Count**	**% Count**
Respiratory complications	2	28.6
Decubitus ulcer and pressure area	1	14.3
Bowel complications	1	14.3
Total	4	57.2

Appendix 6G: Analysis of risk factors

	Age Range				
Risks	**16-30**	**31-45**	**46-60**	**61-75**	**76+**
Alcohol	3	1	0	0	0
Drug	20	25	25	17	5
Tobacco	75	70	29	11	6
Total	98	96	54	28	11

Appendix 6H: Death: Separation by principal diagnosis and LOS

ICD-10-AM	**Count**	**LOS**
Injury of cervical spinal cord unspecific	1	0
Other incomplete cord syndrome cervical spinal cord	1	0
Injury of thoracic spinal cord unspecific	2	0
Functional spinal cord injury, T6/T7	1	5
Functional spinal cord injury, T1	1	11
Functional spinal cord injury cervical level unspecific	2	13
Functional spinal cord injury, C7	1	15
Complete lesion of thoracic spinal cord	1	18
Functional spinal cord injury, C1	3	19
Functional spinal cord injury, C6	7	33
Functional spinal cord injury, C2	8	44
Functional spinal cord injury, T4/T5	4	48
Functional spinal cord injury, C5	9	104
Complete lesion of cervical spinal cord	3	113
Functional spinal cord injury, C3	6	134
Central cord syndrome cervical	4	160
Functional spinal cord injury, C4	14	397