Challenges in Clinical Data Linkage in Australia: 
Perspective of Spinal Cord Injury

Jane Dominique Moon, University of Melbourne, Melbourne, Australia
Megan Bohensky, Royal Melbourne Hospital, University of Melbourne, Melbourne, Australia
Mary Galea, Department of Medicine, Royal Melbourne Hospital, University of Melbourne, Melbourne, Australia

ABSTRACT
Long term and comprehensive management of patients with Spinal Cord Injury (SCI) within the Australian health system suffers from ineffective patient data co-ordination between state and federal levels, between private and public hospitals, and among the allied health sectors, all of which form multiple data custodians. Patients with SCI may require medical intervention over an average of 30-40 years thus it is challenging to keep all the information that belongs to the same person accessible over a prolonged period of time. Although Australia is leading in the data linkage program (e.g. the West Australian Data Linkage Systems, WADLS), it has a long way to go as far as SCI patients are concerned. Here, the authors present findings based on interviews with a range of data custodians for patients with SCI, showing that data are kept in different silos which are not coordinated, hence duplication exists and patient information that exists on many different databases is inconsistently updated. This paper presents information generated by SCI patients and considers the range of data custodians and issues involved in data linkage in Australia, as well as reviewing the WADLS and a new Australian Government initiative called My Health Record system.

KEYWORDS
American Rochester, Better Health Record (BHR), Canadian Manitoba System (CMS), Clinical Data Linkages (CDL), Data Custodians, Oxford Record Linkage System (ORLS), Spinal Cord Injuries (SCI), West Australian Data Linkage Systems (WADLS)

INTRODUCTION
Health care organizations generate large amounts of electronic data through electronic medical records, increasing use of e-prescriptions, digital imaging scans, pharmacy, pathology results, admissions systems, and billing for insurance claims. Patients with spinal cord injury (SCI), through their average life span of 40 years, generate a large amount of health information that is not shared by those who need it; hence very important information may be missing for crucial diagnoses. Clinical Data Linkage (CLD) is one statistical method that can bring that information together.

According to an Australian national initiative, the Population Health Research Network (PHRN), clinical data linkage is defined as:

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...the method by which information about people, places and events from different data collections is brought together (PHRN, 2016).

In other words, data linkage is a technique of linking information that is thought to be related to the same person, family or event. Data linkage is needed because an individual’s driver’s license number, health identifier number and hospital patient number are different and may not be able to connect different services (Christen, 2012). It has been successfully used in population studies and epidemiological studies in medicine for the prediction of diseases, such as effects of smoking on pregnancy (Stavrou, Baker, & Bishop, 2009; Thomson, Glasson, & Bittles, 2006) and treatment of prostate cancer (Goldsbury, Armstrong, Simonella, Armstrong, & O’Connell, 2012).

CDL is particularly important for patients with SCI as their life expectancy, on average, has increased from 34 years to 40 years and is expected to increase further, costing a total of $2 billion or 2% of total health expenditure in 2008 – $5 mil for paraplegia, $9.5 mil for tetraplegia (Access Economics, 2009). Approximately 12.1 to 57.8 million people live with SCI in developed countries (van den Berg et al. 2010). In Australia, there are between 21 and 32 cases per million of traumatic SCI (TSCI) (New, Baxter, Farry, & Noonan, 2015), and 367.2 cases per million of non-traumatic SCI (NTSCI) (New et al., 2015). About 60% are wheelchair dependent (AIHW, 2012). Even though the prevalence of SCI is low, the medical dependence per case is very high and puts a heavy burden on health expenditure (Stepahead, 2016).

Patients with SCI have frequent visits to hospitals and doctors due to associated secondary conditions such as pressure ulcers and urinary tract infections (Dryden et al., 2004; Moon, Galea, & Bohensky, 2015; Norton, 2010; Stepahead, 2016). Many patients with SCI undergo lengthy rehabilitation and are heavily reliant on medical interventions (Gabbe et al., 2016; Norman et al., 2010; Norton, 2010; Wyndaele & Wyndaele, 2006), and many are dependent on social welfare. It is not uncommon for patients to move from one hospital to another, not necessarily confined to one geographic area. Recent trends have shown there has been an increase in mobility of patients with SCI to different states, which makes it difficult to gather information about such patients into one comprehensive information source (ABS, 2011; AIHW, 2012).

Over a life span, a huge amount of data is collected, not only clinical but also administrative and pharmaceutical information that is stored by a range of data custodians who have vested interests in collection of the data, and the items of clinical information are kept in silos (Moon, Hart, & Nunn, 2014). This paper has three aims: firstly, to describe the current state of data collection on SCI in Australia, secondly, to present methods for linking multiple heterogeneous data sources from various custodians, and lastly, to discuss the challenges and future directions involved in effective linkage of SCI data.

Background

An EJourney Through the Life Cycle of Spinal Cord Injury – Multiple Data Custodians

On average, patients with Spinal Cord Injury now have a relatively normal lifespan with over a 40 year of medical dependency and this is expected to rise with improved medical services. A typical scenario of traumatic SCI is described through the eJourney of John, who had an accident while riding a motorcycle on the way to work (Moon et al., 2014). Upon admission to the hospital John’s information was collected by a range of custodians for clinical, statutory and financial purposes as shown in Figure 1.
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Help
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