

Chapter 17

Clinical Data Linkages in Spinal Cord Injuries (SCI) in Australia: What Are the Concerns?

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ABSTRACT

Clinical data linkage amongst patients with Spinal Cord Injury (SCI) is a challenge, as the Australian Health System is fragmented and there is lack of coordination between multiple data custodians at the state and federal levels, private and public hospitals, and acute and allied health sectors. This is particularly problematic in chronic conditions such as SCI, where multiple data custodians collect data on patients over long periods of time. The author presents findings based on interviews with a range of data custodians for SCI categorized as clinical, statutory, and financial data custodians. It is found 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 chapter describes the importance of Clinical Data Linkage for healthcare in predicting disease trajectories for SCI and discusses how administrative and clinical data are collected and stored and some of the challenges in linking these datasets.

INTRODUCTION

Clinical Data Linkage (CDL) is a statistical tool which allows linking of different datasets kept in different locations that relate to the same individual (Christen, 2013). This method has been powerful

in population health in identifying risk factors and evaluating preventative measures and treatments for various diseases.

Medical conditions such as spinal cord injuries (SCI) require high intervention over extended periods of time, and items of medical information

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are not always current, reliable and available to the appropriate person throughout the life span of the person with SCI (NISU, 2013).

Often patients have frequent visits to hospitals and doctors due to associated secondary conditions (Dryden et al., 2004; Norton, 2010). Many SCI patients undergo lengthy rehabilitation and are heavily reliant on medical interventions (Norman et al., 2010; Norton, 2010; Wyndaele & Wyndaele, 2006) and may be 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 to different states, which makes it difficult to gather information about such patients into one comprehensive information source (ABS, 2011; AIHW, 2012).

There is a range of data in addition to the main clinical condition. These include associated information such as pathology reports, radiology and pharmaceutical information. In addition, there is a large amount of administrative information collected and stored by a range of data custodians. All data custodians have vested interests in collection of the data, and the items of clinical information are kept in silos (Moon, 2014).

This chapter has three aims: firstly, to describe the current state of clinical data linkage in Australia and compare it to best practices in other countries, secondly, to present the best possible solution to link multiple heterogeneous data sources from various custodians and lastly, to discuss the challenges involved in effective linkage.

BACKGROUND

What is Clinical Data Linkage?

‘Clinical Data Linkage (CDL)’ or ‘Record linkage’ are terms used interchangeably to describe the process of bringing together two or more records relating to the same individual or entity

(e.g. family). A good example occurs in the health field where cross-referencing of different health information sources occurs. 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 to link two or more sets of data that belonged to the same entities (Fellegi & Sunter, 1969). There have been other methods of record linkage based on vector methods and decision trees but no method has surpassed the Fellegi and Sunter model (Christen, 2013).

CDL is needed because individual identifiers (e.g. an individual driver’s license number, health identifier number, hospital patient number) are unique in different settings and may not be able to connect different services (Christen, 2012; Christen & Churches, 2006). CDL allows information from multiple sources to be joined together to produce richer data sets for research purposes and has wide applicability in public health and epidemiological research.

In SCI, linkage has been used by researchers in predicting mortality after traumatic SCI (Hagen, Lie, Rekand, Gilhus, & Gronning, 2010), survival after the injury (O’Connor, 2005), looking for patterns of morbidity and rehospitalisation after SCI and incidences and patterns (Middleton, Lim, Taylor, Soden, & Rutkowski, 2004),

The following section will explore how data linkage is applied internationally and locally with respect to co-ordination of disparate datasets, and in particular its practical application to making available health information for patient conditions with high medical intervention, e.g. for chronic diseases.

Best Practices of CDL

Many countries have attempted various stages of data linkage. Some have had success and others

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