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# New Zealand Spinal Cord Registry: a new milestone

Christine Howard-Brown, Ian Civil

The Ministry of Health, in its Tertiary Services Review in 1995, identified a number of issues specific to spinal cord impairment (SCI) rehabilitation.<sup>1</sup>

These issues included variable acute care outcomes, an inability to compare data between the two spinal rehabilitation services, and a need for agreed quality measures, together with a method to collect and share them.

Now, more than 20 years later, acute care, and longer-term outcomes for people with SCI are still not systematically collected, and rehabilitation data collection is limited to inpatient data using the Australasian Rehabilitation Outcomes Centre (AROC) register.<sup>2</sup> This means little is known about the true incidence of SCI in New Zealand, or the acute clinical and longer-term outcomes for people with SCI.

The clinical challenges that stem from the absence of a structured SCI registry have been noted by many New Zealand researchers.<sup>3-9</sup> The benefits of clinical registries to systematically collect data has a growing evidence base, demonstrating their value as key instruments for improving patient care, achieving optimal social, economic and quality of life outcomes, supporting health care planning, and for developing clinical research priorities.<sup>10</sup>

As suggested in the paper by Smaill et al in this issue of the *New Zealand Medical Journal*, the benefits of a national SCI registry could also greatly inform planning and delivery of services through improving data access on an otherwise hidden population of people ageing with SCI.

The impetus for a SCI registry has grown and is recognised in the New Zealand Spinal Cord Impairment Action Plan 2014–2019.<sup>11</sup>

The Action Plan, which has eight objectives, includes establishing a national SCI registry as a key activity which will contribute to achieving the best possible health and wellbeing outcomes for people with SCI.

As part of the implementation of the Action Plan, the Burwood Spinal Unit and Burwood Academy of Independent Living completed a 12-month feasibility pilot of two international registries.<sup>12</sup> The pilot recommended adoption of the Rick Hansen Spinal Cord Injury Registry (RHSCIR), a pan-Canadian prospective observational registry which is principally funded by the Federal Government of Canada (Health Canada, Western Economic Diversification Fund). The Action Plan governance group endorsed the pilot's recommendation, which has resulted in sustainable funding from ACC, Counties Manukau and Canterbury District Health Boards for establishing and maintaining a New Zealand RHSCIR. Over the last few months, a registry governance group and two coordinator registry positions have been established, as well as a formal arrangement entered into with RHSCIR. RHSCIR is also working with the New Zealand registry governance group to enable inclusion of non-traumatic spinal cord impairment data and long-term follow-up data, as data collection currently covers each new acute hospital admission to discharge from rehabilitation services. With ethics approval, *a priori* questions and data points confirmed, data entry will commence on 1 August 2016.

This marks an important milestone in the management of SCI in New Zealand, as the NZRHSCIR will support evidence-based quality improvement, including international benchmarking and presents unparalleled research opportunities.

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