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SYDNEY

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**Two Year Participant Outcomes Evaluation Project of the South Australia Lifetime Support Scheme**

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Participant outcomes for the Lifetime Support Scheme were identified and recommendations made on potential outcome measures for future development that would allow direct comparison with other Australian Schemes. All information was extracted from the available electronic records including personal and injury details, and each person's outcomes at 6 months and 2 years post injury. The measures collected included the Functional Independence Measure to assess the functional skills of people with brain injury (TBI) or burns; the Care and Needs Scale (CANS) to measure the level of support required for people with TBI; the American Spinal Injury Association scale to assess the injury level and injury completeness in people with a spinal cord injury (SCI); along with the Glasgow Outcome Coma Score Extended to assess the level of disability for people with TBI.

There was a total of 101 participant referred to the scheme over the period 1<sup>st</sup> July 2014 to 26<sup>th</sup> June 2016; 58 people with a TBI; 21 people with SCI; 19 with amputation (A); and 3 with severe burns.

69.3% were identified as lifetime participants, while 13.9% were not lifetime participants. The remaining 5% were still interim participants, 5% had been suspended and 6.9% were deceased. Participants were primarily young men (77.2%), with relative socio-economic disadvantage, with few recorded as indigenous, non-English speaking backgrounds or having incomplete and low level SCI. Over half of the sample (57.4%) had a TBI. Two thirds of individuals were classified as having a very severe (35%) or extremely severe (31%) injuries based on the duration of post traumatic amnesia (PTA). People with SCI accounted for only 20.8% of the total, being quite equally distributed between paraplegia and tetraplegia. 19% of people had an amputation and 3% had burns.

At follow-up, a positive functional change had occurred within 2 years after-injury for all TBI participants for the mobility items, irrespective of injury type. On average their disability was moderate but still required moderate to minimal assistance for the cognitive components. The longest PTA group had the poorest outcomes. Improvements in level of disability were identified but the SCI group did not show the same improvements. Furthermore, fewer participants were working at 2 years post injury with only 25% of people with TBI working at this time.

Most of the people with amputations came to the scheme 2 to 3 years after their injury, due to a retrospective change in the qualifying criteria. Further, people with below knee amputations were eligible, whilst in NSW eligibility is restricted to people with above knee amputation. The brachial plexus injury criteria also appear less stringent than in NSW.

Expected patterns with reference to types of injury and general patterns of recovery and support requirements were identified. Data from a larger numbers of participants with follow-up for a longer period of time (to five years), along with the addition of further background data, would



allow a more precise evaluation of participant outcomes in the Scheme. The data raised certain questions whether all people who are potentially eligible for the scheme are referred to it. In particular people from indigenous, non English speaking backgrounds and with low level or incomplete SCI may not be referred to the Scheme.

It is recommended that: investigation be performed to identify whether all people potentially eligible for the Scheme are being referred to it; the Spinal Cord Independence Measure (SCIM-R) be adopted as well as a recognised generic quality of life outcome measure (such as WHOQoL BREF). Further, the different support requirements of the three major groups of participants (TBI, SCI, A) be identified, to assist with the planning and development of specific group targeted support activities (as has occurred in other Australian states).