

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Australian stroke survivor and carer needs assessment</b>
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<b>Submission date</b>	21 September 2011
<b>AuSCR role</b>	Survey
<b>Approved</b>	31 December 2011
<b>Status</b>	Completed
<b>Summary</b>	<p>This was the largest and most comprehensive assessment of long-term (&gt; 1 year) unmet needs in community dwelling Australian survivors of stroke and their care givers. The survey was adapted from a similar survey used in the United Kingdom with input from an advisory group. Stroke survivors were asked about the extent to which their needs were being met across six domains: health; everyday living; work; leisure; family/friends and support; and finances. They were also asked about the extent to which having a stroke had impacted on various aspects of their lives and whether or not they were able to access services and support groups. Carers were asked about the impact that taking on a care giver role had on various aspects of their lives.</p>
<b>Outcomes</b>	<p>Over 1,000 stroke survivors and carers participated in the survey. Of these 765 were survivors and 387 were carers. The majority were recruited through hospitals (38%) and 25% were recruited through the Australian Stroke Clinical Registry (AuSCR). Participants were recruited from all States and Territories in Australia.</p> <p>Ninety-six percent (N=731) of all respondents reported having needs. Of these 84% reported one or more need that was not fully met across the six domains measured in the survey. The median number of needs reported by participants as being not fully met was 4 of 20 (Quartile 1, Quartile 3 (Q1, Q3): 1, 9). A greater proportion of young stroke survivors (&lt; 65 years of age) and those with substantial disability reported having needs that were not fully met. Health needs were the most common type of need with 84% reporting health needs that were not fully met. Within the category of health, needs in the areas of concentration, cognition, memory, fatigue and emotions were the least likely to be met. Over half of all stroke survivors reported experiencing moderate to extreme changes in their leisure activities and two out of three participants who required assistance returning to leisure activities reported that their needs in this area were not fully met. Three out of four stroke survivors that were working prior to their stroke reported changes in their work situation. Two thirds of those that needed assistance returning to work reported that their work needs were not fully met. Moderate to extreme changes in spousal relationships (34%), family relationships (23%) and relationships with friends and people outside the family (31%) were reported by stroke survivors. Most carers (87%) lived with the stroke survivors and the majority, three out of four, were women.</p> <p>Around half reported having experienced moderate to extreme changes in their work and leisure activities since taking on a carer role. These data provided evidence that our current health systems and community services are not sufficiently meeting many of the needs considered to be most important to stroke survivors and their carers.</p>
<b>Publications</b>	<ol style="list-style-type: none"> <li>Andrew NE, Kilkenny M, Naylor R, Purvis T, Lalor E, Moloczij N, Cadilhac DA. <b>Understanding long-term unmet needs in Australian survivors of stroke.</b> <i>International Journal of Stroke</i> 2014; 9:106–12. <a href="https://www.ncbi.nlm.nih.gov/pubmed/25042019">https://www.ncbi.nlm.nih.gov/pubmed/25042019</a></li> <li>Andrew NE, Kilkenny MF, Naylor R, Purvis T, Cadilhac DA. <b>The relationship between caregiver impacts and the unmet needs of survivors of stroke.</b> <i>Patient Preference Adherence</i> 2015;9:1065-73. <a href="https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4524576">https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4524576</a></li> <li>Andrew NE, Kilkenny MF, NA Lannin, E Lalor, and Cadilhac DA. <b>Is health related quality of life between 90 and 180 days following stroke associated with long-term unmet needs?</b> <i>Quality of Life Research</i> 2016;25, 2053-62 <a href="https://www.ncbi.nlm.nih.gov/pubmed/26847339">https://www.ncbi.nlm.nih.gov/pubmed/26847339</a></li> </ol>