

AuSCR Research Task Group approved projects

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| Title | Exploring the unmet needs of people who provide support to survivors of stroke: a national survey |
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| AuSCR role | Recruitment |
| Approved | 8 July 2023 |
| Status | In progress |

Summary Primary support people (also known as informal caregivers) are often essential to people living with stroke in the community. The support person role can involve assistance with daily activities e.g. shopping, bathing, transportation, as well as providing emotional support often without financial compensation. Unmet needs are often experienced by support people when health services are perceived to be inadequate to manage the health condition of the survivor or themselves. Experiencing unmet needs can result in adverse health outcomes for the support person and the survivor of stroke. This can include poorer mental health or overall quality of life. Identifying unmet needs of the support person, as well as strategies that they have been using to fix unmet needs, will provide important information for the planning and developing improved community services and additional support strategies. The overall objective of this project is to provide a contemporary view of unmet needs of people who provide support to survivors of stroke within Australia. This information will be used to understand how health and community services sectors can be modified to better meet the needs of support people after stroke; and whether the type and frequency of the various unmet needs has changed over time.

The survey has been developed for the current project is based on the Carer Needs Survey from the Australian Stroke Survivor and Carer Needs Assessment Survey that had 19 questions assessing the unmet needs for support persons of survivors of stroke. Recognising that support services and features of unmet needs for support people may have changed, including terminology since 2011, we have reviewed and changed the wording for multiple questions and answers from the original Australian Stroke Survivor and Carer Needs Assessment Survey. Further, additional questions have been added into the current survey. The primary recruitment approach will be through Australian Stroke Clinical Registry (AuSCR). Support people will be identified using the AuSCR, coordinated at the Florey Institute of Neuroscience and Mental Health, by first identifying survivors of stroke that have agreed at their AuSCR 90-180 day follow-up survey to be contacted for research projects. The AuSCR collects data from participating hospitals to monitor and improve the quality of acute stroke care (<http://www.auscr.com.au/>). The pack sent to the participants will include a cover letter, participant information sheet, survey, return envelope, a decline to participate form, and a preferred method of completion form.

Participants will be provided the options for completion of the support person survey either (i) using the paper survey, or (ii) via an online form with a URL link that can be used on a personal computer or SmartPhone/Ipad, or (iii) over the telephone by returning a telephone information form. In order to be eligible to participate in the survey, the support person needs to be: aged 18 years and over, identify as assisting a survivor of stroke who is independently living in the community, be able to complete a questionnaire within the project timeframe.