AuSCR Research Task Group approved projects

Title	**Improving life after stroke with tailored support: Innovation in use of national registry data (A-LISTS)**
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AuSCR role	Recruitment
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Status	In progress
Summary	Many people living with stroke have ongoing disability and report extreme problems in different domains of quality of life up to six months following stroke. Of concern is that the majority have also reported that their long-term needs are unmet two years after stroke. Our project has received seed funding from the Medical Research Future Fund. Since 2009, the AuSCR has collected over 60,000 patient-reported outcome (PRO) surveys between 90 – 180 days after admission. The data are summarised and reported in the Annual report; and hospital clinicians can access a summary report for their patients or directly download individual patient-level data. It remains unclear whether access to these data by clinicians has been used to inform patient management. Using data from the Australian Stroke Clinical Registry, we have identified factors associated with an increased risk of returning to the hospital and poor quality of life. We now seek to design and trial the feasibility of a hospital-initiated follow-up service to act on the patient outcome data for people who respond to having extreme problems or unmet needs. Our mechanism for doing this will be with the hospitals that have provided patient data for the registry, as we do not collect information about general practitioners the patient is seeing. The A-LISTS project will target people who report an extreme problem, as measured on the EQ-5D or have an overall HR-QoL score on the Visual Analogue Scale (VAS) below 60 (0 is worst imaginable health and 100 is best health), on the 90-180 days post stroke AuSCR survey. In the first year of this two-year project, the multidisciplinary team (including consumer representatives) will co-design the intervention and conduct preliminary testing in one AuSCR hospital and refinements. We will then refine the clinical protocol so that is can be piloted in a randomised controlled trial in up to six hospitals and 100 patients. We will determine whether the use of registry data will enable hospital and community-based clinicians to better tailor their stroke follow-up service and improve liaison with primary care or community-based health professionals. The specific tools this project will establish include i) an electronic report established within the AuSCR data infrastructure to flag eligible registrants who meet the eligibility criteria for the new follow-up service; and ii) a generic clinical protocol and guidance document for conducting the follow-up service that can be adapted to be tailored to the requirements of the hospital and local resources. The evidence we generate from this Incubator project will provide the information and tools to support broader application of the program for stroke, as well as provide an exemplar for other clinical quality registries. Research aims: To design a hospital-initiated follow-up service for people with stroke who report high levels of unmet health needs, post-discharge, including: a. An electronic data feedback report that can be integrated with the AuSCR to flag the registrants who meet the criteria for the follow-up service b. A clinical protocol and guidance document that enables different modes of delivery, such as in-person or via telehealth. Using a pilot randomised controlled design in up to 6 hospitals (n=50 intervention, n=50 control group), to evaluate the potential of the hospital-initiated follow-up service for: a. feasibility in different hospitals b. acceptability to people with stroke c. effectiveness d. cost implications