

# AuSCR Research Task Group approved projects

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## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Healthy living after stroke: An online intervention for improving stroke survivor health behaviours and quality of life</b>
<b>Principle investigator</b>	Associate Professor Billie Bonevski
<b>Institute</b>	Centre for Translational Neuroscience and Mental Health, University of Newcastle
<b>Co-investigators</b>	Professor Neil Spratt, Associate Professor Michael Pollack, Professor Amanda Baker, Professor Parker Magin, Dr Alyna Turner, Dr Christopher Oldmeadow, Professor Clare Collins, Professor Robin Callister, Dr Ashleigh Guillaumier, Conjoint Professor Andrew Searles, Conjoint Professor Chris Levi, Ms Alexandra Denham, Dr Olivia Wynne
<b>Submission date</b>	1 August 2017
<b>AuSCR role</b>	Participant recruitment
<b>Approved</b>	17 October 2017
<b>Status</b>	In progress
<b>Summary</b>	This project addresses the health information needs and behaviour change challenges of stroke survivors. This study will build on pilot research. Our NSF funded online "Prevent 2nd Stroke" programme aims to improve stroke survivors' health risk behaviours, quality of life, depression and anxiety, and independent living, while at the same time lowering their risk of recurrent stroke. The programme incorporates evidence based behaviour change strategies and cognitive behaviour therapy. Stroke survivors have rated the programme positively on useability, acceptability and perceived effectiveness. However no large, definitive trials of online health behaviour interventions for stroke survivors have been published. This project will test the effectiveness of the programme using randomised controlled trial design.

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Identifying gaps and inequalities in access to General Practitioner coordinated care for survivors of stroke</b>
<b>Principle investigator</b>	Dr Nadine Andrew
<b>Institute</b>	Stroke and Ageing Research Centre, Monash University
<b>Co-investigators</b>	Associate Professor Dominique Cadilhac, Professor Amanda Thrift, Associate Professor Vijaya Sundararajan
<b>Submission date</b>	8 March 2017
<b>AuSCR role</b>	Data Provision
<b>Approved</b>	17 October 2017
<b>Status</b>	In progress
<b>Summary</b>	<p>The aim of this study is to conduct an observational cohort study using comprehensive linked data from survivors of stroke registered in the Australian Stroke Clinical Registry (AuSCR) linked to Medical benefit Schedule (MBS or Medicare), and Pharmaceutical Benefit Scheme (PBS) data to:</p> <ol style="list-style-type: none"> <li>1) Describe how patients with stroke are managed in the community following discharge from hospital. This will be done using Medicare funded items relating to care coordination (e.g. CDMPs and TCAs), reimbursement items relevant to managing common sequelae of stroke (e.g. depression and pain) and provision of medications relevant to stroke prevention and management in the 1-2 years following stroke.</li> <li>2) Describe patient factors (e.g. age, location, ethnicity), clinical factors (e.g. stroke type, disability profile) and system factors (e.g. early rehabilitation, pre-stroke GP care, cost of care/medication) associated with different care types following stroke.</li> <li>3) Describe patient factors (e.g. age, location, ethnicity), clinical factors (e.g. stroke type, disability profile) and system factors (e.g. early rehabilitation, pre-stroke GP care, costs of care) associated with receipt or no receipt of GP coordinated rehabilitation (defined as receipt of a TCA or a TCA review) in those with chronic disability.</li> </ol>

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>An investigator-initiated, prospective, feasibility study to describe the occurrence of Fabry disease in people, aged 18 to 55 years, living with stroke in the community in Australia</b>
<b>Principle investigator</b>	Professor Craig Anderson
<b>Institute</b>	The George Institute for Global Health
<b>Co-investigators</b>	Associate Professor Dominique Cadilhac, Professor Vincent Thijs, Ms Brenda Grabsch, Ms Joyce Lim, Dr Alejandra Malavera
<b>Submission date</b>	2 February 2017
<b>AuSCR role</b>	Participant recruitment
<b>Approved</b>	23 May 2017
<b>Status</b>	In progress
<b>Summary</b>	<p>Stroke in the young (18-55 years) represents about half of the total disability burden of stroke in Australia. Among the broader causes of stroke in the young, genetic disorders such as Fabry disease are of significant importance for investigation.</p> <p>One of the serious clinical manifestations of Fabry disease is stroke. The mechanisms underlying the pathogenesis of stroke in Fabry disease have not been clearly delineated. Currently in Australia, awareness of Fabry disease as a stroke risk factor among clinicians is low, and screening and detection are more ad hoc ('opportunistic') rather than systematic, so there is likely to be a high level of unmet need and the prevalence is uncertain.</p> <p>The primary aim of this study is to determine the feasibility of screening for Fabry disease among people aged 18-55 years, living in the community after stroke and registered in the Australian Stroke Clinical Registry (AuSCR).</p>

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Inspiring Virtual Enabled Resources following Vascular Events (iVERVE) pilot project</b>
<b>Principle investigator</b>	Associate Professor Dominique Cadilhac
<b>Institute</b>	The Florey Institute of Neuroscience and Mental Health/ Stroke and Ageing Research Centre, Monash University
<b>Co-investigators</b>	Dr Nadine Andrew, Professor Amanda Thrift, Dr Monique Kilkenny, Dr Jonathan Li, Professor Ian Kneebone, Associate Professor Maree Hackett, Dr Doreen Busingye
<b>Submission date</b>	20 August 2016
<b>AuSCR role</b>	Participant Recruitment/Survey
<b>Approved</b>	28 February 2017
<b>Status</b>	In progress
<b>Summary</b>	<p>Our aims are to:</p> <ol style="list-style-type: none"> <li>1. Design, build and pilot test a personalised electronic self-management support intervention for patient-centred goal attainment and secondary prevention following stroke.</li> <li>2. Determine the acceptability and feasibility of the proposed intervention in a sample of survivors of stroke and modify the design of components, as required.</li> <li>3. Perform a phase 2 pilot study to obtain data for estimating the sample size required for a large-scale randomised-controlled trial to test the likely effectiveness of the intervention for positively changing patient outcomes.</li> </ol>

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Emerging Treatments for Stroke Survey</b>
<b>Principle investigator</b>	Professor Jane Mathias
<b>Institute</b>	University of Adelaide
<b>Co-investigators</b>	Mr David Unsworth, Dr Diana Dorstyn, Professor Simon Koblar
<b>Submission date</b>	21 October 2016
<b>AuSCR role</b>	Survey
<b>Approved</b>	15 March 2017
<b>Status</b>	Completed
<b>Summary</b>	Australian stroke survivors were surveyed to: (1) measure treatment and service-related satisfaction; (2) explore their perceptions and attitudes (e.g., level of interest, perceived risks/benefits, preferred cell/procedure types, desired outcomes, areas of concern, main sources of information, need for additional information) toward cell therapies; and (3) examine whether factors relating to treatment satisfaction, disability severity (e.g., physical/cognitive/psychological, disease duration), social support, attitudes towards cell therapies, and demographics (e.g., age, sex) increase the likelihood that they will consider having these experimental treatments.
<b>Outcomes</b>	AuSCR mailed 500 paper-based surveys to members, from which 69 responses were received (13.8% response rate). Eight Australian stroke advocacy organisations (e.g. Stroke Foundation) and stroke support groups (e.g. Young Stroke Group) also promoted the survey among their members, which resulted in a further 114 responses (N=183). The results of the survey indicated that the majority of respondents were happy with the inpatient and outpatient services they had received for their strokes. In terms of stem cell treatments, most respondents were unsure about the safety/effectiveness and accessibility/affordability of stem cell treatments (SCTs), but despite this, 25% (n=46) of respondents were still considering having these experimental treatments. Specifically, participants with positive SCT attitudes (odds ratio [OR]=1.22), longer post-stroke intervals (OR=1.08), perceived caregiver burden (OR=1.07), poorer physical independence (OR=.95) and younger ages (OR=.96) were most likely to be considering SCTs. Therefore, it is recommended that clinicians working with stroke survivors remain mindful of these factors when discussing treatment options.
<b>Publications</b>	Unsworth, DJ, Mathias, JM, Dorstyn, DS, & Koblar, SA. (2018) Stroke survivor attitudes toward, and motivations for, considering experimental stem cell treatments. <i>Manuscript currently under review for publication in an international peer-reviewed journal.</i>

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>John Hunter Hospital (JHH) and Tamworth Rural Referral Hospital (TRRH) Stroke Mortality Independent Report</b>
<b>Principle investigator</b>	Professor Chris Levi
<b>Institute</b>	John Hunter Hospital
<b>Co-investigators</b>	Ms Louise Jordan, Dr Neil Spratt, Mr Malcolm Evans, Ms Annalese Johnson
<b>Submission date</b>	13 September 2016
<b>AuSCR role</b>	Data provision and analysis
<b>Approved</b>	18 January 2017
<b>Status</b>	Completed
<b>Summary</b>	<p>A Bureau of Health Information (BHI) Unwarranted Clinical Variation Report including Stroke Mortality at 30 days will be published in November 2016. A previous BHI Report published in 2013 showed both the John Hunter Hospital (JHH) and Tamworth Rural Referral Hospital (TRRH) as having higher than state level stroke mortalities.</p> <p>In preparation for the 2016 release of data, HNELHD Hub Stroke Services would like to seek an independent evaluation of HNELHD 30 day mortality compared to peer hospitals and adjusted for stroke severity. It is proposed that the Australian Stroke Clinical Registry (AuSCR), which is a national data registry that evaluates stroke outcomes including mortality and service delivery be utilised in this process.</p>
<b>Outcomes</b>	The results as described above allowed the HNE Stroke Steam to provide an evidence-based response to reassure the HNE LHD senior management as to the standard of stroke care in their organisation and to “educate” the NSW BHI on best practice methods for standardised mortality rate adjustment.
<b>Publications</b>	<p>The report was used for internal purposes, however, this work stimulated interest and contributed to the 2017 MJA publication from the AuSCR team.</p> <p>Cadilhac DA, Kilkenny MF, Levi CR, Lannin NA, Thrift AG, Kim J, Grabsch B, Churilov L, Dewey HM, Hill K, Faux SG, Grimley R, Castley H, Hand PJ, Wong A, Herkes GK, Gill M, Crompton D, Middleton S, Donnan GA, Anderson CS. Risk-adjusted hospital mortality rates for stroke: evidence from the Australian Stroke Clinical Registry (AuSCR). <i>Med J Aust</i> 2017 May 1;206(8):345-350 Open Access doi: 10.5694/mja16.00525</p> <p>The outcomes of this commissioned report were commented on by Dr Norman Swan on the Radio National Health report – <a href="http://www.abc.net.au/radionational/programs/healthreport/using-data-to-choose-your-hospital/8486908">http://www.abc.net.au/radionational/programs/healthreport/using-data-to-choose-your-hospital/8486908</a></p>

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Inspiring Virtual Enabled Resources following Vascular Events (iVERVE) pilot project</b>
<b>Principle investigator</b>	Associate Professor Dominique Cadilhac
<b>Institute</b>	The Florey Institute of Neuroscience and Mental Health/ Stroke and Ageing Research Centre, Monash University
<b>Co-investigators</b>	Dr Nadine Andrew, Professor Amanda Thrift, Dr Monique Kilkenny, Dr Jonathan Li, Professor Ian Kneebone, Associate Professor Maree Hackett, Dr Doreen Busingye
<b>Submission date</b>	20 August 2016
<b>AuSCR role</b>	Participant Recruitment/Survey
<b>Approved</b>	28 February 2017
<b>Status</b>	In progress
<b>Summary</b>	<p>Our aims are to:</p> <ol style="list-style-type: none"> <li>4. Design, build and pilot test a personalised electronic self-management support intervention for patient-centred goal attainment and secondary prevention following stroke.</li> <li>5. Determine the acceptability and feasibility of the proposed intervention in a sample of survivors of stroke and modify the design of components, as required.</li> <li>6. Perform a phase 2 pilot study to obtain data for estimating the sample size required for a large-scale randomised-controlled trial to test the likely effectiveness of the intervention for positively changing patient outcomes.</li> </ol>



## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Healthy Living After Stroke: Pilot study of an online secondary prevention program for stroke survivors</b>
<b>Principle investigator</b>	Associate Professor Billie Bonevski
<b>Institute</b>	Centre for Translational Neuroscience and Mental Health, University of Newcastle
<b>Co-investigators</b>	Dr Ashleigh Guillaumier, Ms Alexandra Denham, Dr Sean Halpin, Ms Laura Twyman
<b>Submission date</b>	11 May 2016
<b>AuSCR role</b>	Participant recruitment
<b>Approved</b>	19 August 2016
<b>Status</b>	Completed
<b>Summary</b>	<p>The study examined the usability and acceptability of an online program addressing modifiable psycho-behavioural risk factors for stroke survivors. A pre-post pilot study was conducted. Participants recruited through AuSCR completed measures of health-related quality of life, physical activity, smoking status, depression and anxiety, alcohol status, nutrition, and internet use. Participants also used an online secondary prevention program (Prevent 2nd Stroke) over a two-week period. 18 of 19 participants reported engaging in multiple health risk behaviours. Participants reported they were interested in receiving an online program providing health information (73.7%), and that Prevent 2nd Stroke was easy to use (63.1%) and they would recommend the program to other stroke survivors (63.1%).</p>
<b>Outcomes</b>	<p>Of the 200 people who were contacted through AuSCR during the study period, 110 people (55%) responded, and 40 (20%) were eligible to participate in the study. Of those who were eligible, 33 (82.5%) people consented, and 19 (47.5%) people completed both the baseline and follow-up.</p> <p>We found that online secondary prevention programs for stroke survivors are acceptable and feasible. As stroke survivors are still engaging in unhealthy behaviours post-stroke, more research is needed to determine the effectiveness of Prevent 2nd Stroke (P2S) as a health behaviour change intervention. Therefore, the next step in this research is to conduct an effectiveness trial. If effective, online programs have the potential for widespread dissemination to the public through peak organisations such as the National Stroke Foundation (NSF) website. The NSF, has a consumer portal in which stroke survivors can find support through resources about stroke and also access an online community of stroke survivors who share their experiences. As a large percentage of stroke survivors are discharged from hospital without a plan, the P2S could be provided to stroke survivors following discharge. The program could be accessed through the NSF portal, and assist in the promotion of positive lifestyle changes. Furthermore P2S could also allow stroke survivors to receive professional and communal support to reduce the risk of having a second stroke.</p> <p>We have recently launched the large scale effectiveness trial with recruitment via an AuSCR mail out.</p>
<b>Publications</b>	<p><b>Published/presented:</b> Denham, A. M., Halpin, S. , Twyman, L. , Guillaumier, A. and Bonevski, B. (2018), Prevent 2<sup>nd</sup> Stroke: a pilot study of an online secondary prevention program for stroke survivors. Australian and New Zealand Journal of Public Health. . doi:<a href="https://doi.org/10.1111/1753-6405.12794">10.1111/1753-6405.12794</a></p> <p><b>In preparation:</b> Abstract Submission for presentation at Stroke 2018 - The Stroke Society of Australasia (SSA) 28th Annual Scientific Meeting and the 14th Smart Strokes Australasian Nursing and Allied Health Stroke Conference.</p>

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Building efficient and equitable pathways to and through rehabilitation in stroke: BEEPRS</b>
<b>Principle investigator</b>	Dr Rohan Grimley
<b>Institute</b>	Queensland Health
<b>Co-investigators</b>	Mrs Ingrid Rosbergen, Dr Suzanne Kuys, Dr Louise Gustafsson, Dr Eleanor Horton, Dr Benjamin Chen, Professor Theresa Green, Mr Greg Cadigan and Mrs Kerry Marnane
<b>Submission date</b>	8 April 2016
<b>AuSCR role</b>	Data provision
<b>Approved</b>	28 February 2017
<b>Status</b>	Completed
<b>Summary</b>	<p>The Queensland State-wide Stroke Clinical Network (SSCN) has developed a platform of systematic data collection in acute stroke through the Australian Stroke Clinical Registry (AuSCR), which, from mid-2016, will be hosted within the new integrated data collection solution - the Australian Stroke Data Tool (AuSDaT). AuSDaT enables additional data collection at any point along the continuum, which, if linked to AuSCR data can include community outcomes at 3-6 months after acute stroke.</p> <p>This provides a unique opportunity to systematically map current processes and pathways of assessment, referral and provision of rehabilitation through to patient reported outcomes. The resulting information will enable for the first time, a mechanism to establish service gaps in rehabilitation provided to stroke survivors; and inform the most efficient and effective means of configuring rehabilitation services to meet needs and maximise flow from acute hospitals through rehabilitation to the community.</p>
<b>Publications</b>	Grimley R., Rosbergen I., Kuys S., Gustafsson L., Horton E., Green T., Fitzhenry S., Longmire A., Smith M., Hughes B., Wilding R., Brickhill C. and Cadigan G. Determinants of rehabilitation assessment and referral following acute stroke. Early results from Building Efficient and Effective Pathways to and through Rehabilitation after Stroke (BEEPRS). <i>International Journal of Stroke</i> 2017 Vol 12 (3S): p3-59. (Oral presentation)

<b>Title</b>	<b>Sex differences in management and outcomes after stroke in the Australian Stroke Clinical Registry (AuSCR)</b>
<b>Principle investigator</b>	Dr Seana Gall
<b>Institute</b>	University of Tasmania
<b>Co-investigators</b>	Dr Hoang Phan, Associate Professor Dominique Cadilhac, Professor Leigh Blizzard, Professor Amanda Thrift, Professor Mathew Reeves,
<b>Submission date</b>	8 April 2016
<b>AuSCR role</b>	Data provision
<b>Approved</b>	8 August 2016
<b>Status</b>	Completed
<b>Summary</b>	We examined all first-ever stroke cases registered in the AuSCR database from 2010-2014 to model sex differences in in-hospital management, health-related quality of life (HRQoL) using the EQ5D at 3 to 6 months and survival up to 12 months after stroke from the National Death Index. Central to our aims were the examination of a range of factors, mostly at the level of the patient, which might explain the sex differences. These included socio-demographic and stroke-related factors, stroke severity, stroke type, and clinical management.
<b>Outcomes</b>	<p>We included first-ever strokes admitted to 39 hospitals in the AuSCR during 2010-2014. Data were available for 14,118 strokes (46% women, 81% ischaemic, median age: 75). Women were 7 years older and less able to walk on admission (29% vs 37%, <math>p&lt;0.001</math>) than men.</p> <p><b>Sex differences in access to evidence-based therapies in hospital</b></p> <ul style="list-style-type: none"> <li>It appeared that slightly fewer women than men were admitted to a stroke unit (79% vs 81%, <math>p=0.001</math>). Compared to men, women were slightly less often discharged home (47.6% vs 39.6%, <math>p&lt;0.001</math>) and more often discharged to aged-care setting (9.0%, vs 3.8%, <math>p&lt;0.001</math>).</li> <li>Women and men were equally likely to receive thrombolysis (12.7% vs 12.0%, <math>p=0.311</math>), antihypertensive agents (71.1% vs 70.3%, <math>p=0.415</math>) or a care plan at discharge (65.8 vs 68.5, <math>p=0.050</math>).</li> <li>The only difference in evidence-based therapy was that women were less often administered aspirin <math>\leq 48</math> hours (51% vs 58%, <math>p=0.014</math>) in a Queensland subset (<math>n=5,224</math>).</li> </ul> <p><b>Sex differences in long-term mortality after stroke</b></p> <ul style="list-style-type: none"> <li>Mortality was greater in women (mortality rate ratio; <math>MRR_{crude}</math> 1.45 [95% CI 1.33, 1.59]) by 1 year compared to men. The difference was explained by women's greater age and more severe stroke with the adjusted MRR attenuated after accounting for these factors (MRR 1.00; 95% CI 0.92-1.09)</li> </ul> <p><b>Sex differences in long-term health-related quality of life after stroke</b></p> <ul style="list-style-type: none"> <li>About 60% (<math>n=6852</math>) of people in AuSCR had HRQoL assessments. The association between sex and HRQoL depended on age, with only older women having poorer HRQoL than older men (EQ5D utility mean difference [MD] -0.103 [-0.160, -0.047]) independent of severity. Evidence-based care measures did not contribute to the difference.</li> </ul> <p><b>Summary</b></p> <p>Worse outcomes in women compared to men after stroke were associated with age, severity and aspirin administration suggesting targets to reduce sex differences in outcomes.</p>
<b>Publications</b>	<p><b>Published/presented:</b></p> <ol style="list-style-type: none"> <li>Phan HT, Blizzard L, Reeves MJ, Thrift AG, Cadilhac D, Sturm J, Heeley E, Feigin V, Parmar P, Krishnamurthi R, Barker-Collo S, Parag V, Konstantinos V, Anderson C, Bejot Y, Cabral N, Carolei A, Sacco S, Chausson N, Olindo S, Silva C, Correia M, Magalhães R, Appelros P, Korv J, Vibo R, Minelli C, Otahal P, Gall S. <b>Differences Between Men and Women in Long-term Participation Restriction After Stroke: The International Stroke Outcomes Study (INSTRUCT)</b>. Stroke. 2017;48(suppl</li> </ol>

	<p>1):ATP171. International Stroke Conference, Houston, Texas, USA, 2017 (Poster presentation)</p> <p>2. Phan HT, Cadilhac D, Thrift AG, Blizzard L, Anderson C, Kim J, Gall S. <b><i>Differences in Stroke Management do not Account for the Greater Long-term Mortality After Stroke in Women Compared to Men: Australian Stroke Clinical Registry (AuSCR).</i></b> Stroke. 2017;48(suppl 1):ATP171. International Stroke Conference, Houston, Texas, USA, 2017 (Oral presentation)</p> <p>3. Gall SL, Phan HT, Cadilhac D, Blizzard L, Thrift AG, Anderson C, Kim J, Lannin N. <b><i>Poorer quality of life at 3-6 months after stroke in women compared to men is due to age and severity but not clinical care.</i></b> European Stroke Journal. 2017;2:66. European Stroke Organisation Conference, Prague, Czech Republic, 2017 (Oral presentation)</p> <p>4. Phan HT, Cadilhac D, Blizzard L, Lannin N, Thrift AG, Anderson C, Kim J, Grimley R, Gall SL. <b><i>Differences in stroke care and outcomes after stroke for women compared to men: Australian Stroke Clinical Registry (AuSCR).</i></b> The 27th Annual Scientific Meeting of the Stroke Society of Australasia, August 2017, Queenstown, New Zealand (Oral presentation)</p> <p>5. Phan HT, Gall SL, Blizzard L, Lannin NA, Thrift AG, Anderson C, Kim J, Cadilhac DA. <b><i>Lower Health-Related Quality of Life (HRQoL) At 3-6 Months After Stroke in Both Women and Men Compared to Those Without Stroke: An Observational Study From The Australian Stroke Clinical Registry (AuSCR). Stroke. 2018;49(Suppl 1):ATP175).</i></b> International Stroke Conference, 2018, Los Angeles, USA (Poster presentation)</p> <p>6. Phan HT, Gall SL, Blizzard CL, Lannin NA, Thrift AG, Anderson CS, Kim J, Grimley R, Castley HC, Cadilhac DA* on behalf of the AuSCR Consortium. <b><i>Sex difference in specific-cause mortality after stroke: the Australian Stroke Clinical Registry.</i></b> European Stroke Organisation Conference 2018, Gothenburg, Sweden (accepted for a poster presentation in May 2018)</p> <p>We also Submission an abstract to the World Stroke Congress in Montreal, Canada (October 2018) with details below: Phan HT, Gall SL, Blizzard CL, Lannin NA, Thrift AG, Anderson CS, Kim J, Grimley R, Castley HC, Cadilhac DA* on behalf of the AuSCR Consortium. <b><i>Sex difference in specific-cause of excess death rates after stroke: the Australian Stroke Clinical Registry (AuSCR).</i></b></p> <p><b>In preparation:</b></p> <ol style="list-style-type: none"> <li>1. Differences in stroke care and mortality after stroke for women compared to men: Australian Stroke Clinical Registry (AuSCR)</li> <li>2. Sex difference in health-related quality of life at 3 months: Australian Stroke Clinical Registry</li> </ol>
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## AuSCR Research Task Group approved projects

<b>Title</b>	<b>A Comparison of Compensatory and Restorative Approaches to Memory Rehabilitation Post-Stroke</b>
<b>Principle investigator</b>	Dr Rene Stolwyk
<b>Institute</b>	School of Psychological Sciences, Monash University
<b>Co-investigators</b>	Ms Toni Withiel, Dr Dana Wong, Professor Jennie Ponsford & Associate Professor Dominique Cadilhac
<b>Submission date</b>	5 August 2015
<b>AuSCR role</b>	Participant recruitment
<b>Approved</b>	2 December 2015
<b>Status</b>	Completed
<b>Summary</b>	Cognitive impairments post-stroke are common, reported in up to 91.5% of patients with stroke pathology. Memory impairments are one of the most common cognitive sequelae, yet help with this impairment continues to remain a high unmet need within the community. Both restorative and compensatory approaches have been used to remediate memory difficulties post-stroke. Despite decades of research, there is no clear consensus as to which approach is more effective in rehabilitating memory deficits following stroke. This study aimed to explore and contrast the effectiveness of restorative and compensatory approaches to memory rehabilitation post stroke.
<b>Outcomes</b>	<p>One-hundred and thirty-six individuals responded to advertisement (30% recruited via AuSCR). Seventy-one individuals were excluded from participation (52% exclusion). The remaining 65 individuals consented to participate and were randomised into one of three treatment arms (waitlist control (WC), memory skills group (MSG) or computerised cognitive training (CCT)). Participants in the intervention groups (MSG or CCT) received six weeks of a memory intervention.</p> <p>The primary outcome measure was attainment of individualised, functional memory goals, assessed using Goal Attainment Scaling (GAS). Secondary outcomes explored change on objective, neuropsychological measures of memory, subjective ratings of forgetfulness and use of internal and external memory strategies. Participants completed outcome assessment at three time points: baseline, post intervention and at a six week follow-up. Findings suggested that participants allocated to the MSG reported significant improvement in goal attainment above WC participants following intervention. These gains were maintained at a six week follow up, with participants showing significant improvement beyond CCT and WC participants. While participants in the CCT group described some increase in goal attainment, performance did not improve beyond WC at any time point.</p> <p>Regarding secondary outcomes, findings did not provide support for the sustained effects of either intervention on objective measures of memory. There were short term effects of both CCT and MSG training on subjective ratings of forgetfulness, but these were not maintained at follow up. Finally, while all participants reported a significant increase in internal strategy use over time, improvement was only maintained for participants allocated to the MSG. This interaction was not seen for external strategy use. These Phase II data indicate MSG rehabilitation was effective in improving functional goal attainment and internal strategy use. Importantly, gains were maintained and consolidated by six weeks. In contrast, CCT did not result in a significant improvement on functional, objective or subjective measures of memory.</p>
<b>Publications</b>	<ol style="list-style-type: none"> <li>1. Withiel et al., (2018). Comparing Compensatory and Restorative Memory Rehabilitation Following-Stroke: A Phase II Randomised Controlled Trial. <i>Submission to the International Journal of the Neuropsychological Rehabilitation for consideration in January 2018.</i></li> <li>2. Withiel et al., (June 2017). A comparison of compensatory and restorative approaches to memory rehabilitation post-stroke: A phase II randomised controlled trial. <i>Australasian Society for Brain Impairment (ASSBI), Melbourne Australia.</i></li> <li>3. Withiel et al., (July, 2017). A comparison of Restorative and compensatory approaches To memory Rehabilitation post-stroke (RESTORE): A Phase II Randomised Controlled Trial. <i>International Neuropsychology Society (INS), Cape Town South Africa</i></li> </ol>

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Health risk behaviours of stroke and TIA survivors and their informal carers</b>
<b>Principle investigator</b>	Associate Professor Billie Bonevski
<b>Institute</b>	Centre for Translational Neuroscience and Mental Health, University of Newcastle
<b>Co-investigators</b>	Dr Tim Regan, Ms Laura Twyman, Associate Professor Michael Pollack, Professor Amanda Baker, Dr Alyna Turner, Professor Chris Levi
<b>Submission date</b>	3 July 2014
<b>AuSCR role</b>	Participant recruitment
<b>Approved</b>	25 November 2014
<b>Status</b>	Completed
<b>Summary</b>	This study aimed to measure health risk behaviours, depression and anxiety, and preferences for types of health behaviour change interventions amongst community-dwelling stroke survivors. A cross-sectional survey assessed self-reported smoking, alcohol use, physical activity, fruit and vegetable intake, psychological distress, perceived priorities for addressing health risks and preferences for types of health behaviour change interventions.
<b>Outcomes</b>	Participants (n = 83) were aged 24-97 years, and mostly male (62.7%). Health risk behaviours were low levels of fruit and vegetable intake (83.1%), physical inactivity (65%), tobacco smoking (6%), and psychological distress (23%). 78% reported two or more health risk behaviours. Forty-three percent of participants reported no preference for the type of prevention intervention they might use to help them be healthier.
<b>Publications</b>	<b>Paper in preparation:</b> A cross sectional survey of health risk behaviours, psychological distress and intervention preferences among Australian stroke and transient ischemic attack survivors

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>The impact of discharge planning on post-discharge stroke outcomes</b>
<b>Principle investigator</b>	Dr Nadine Andrew
<b>Institute</b>	Stroke and Ageing Research Centre, Monash University
<b>Co-investigators</b>	Associate Professor Dominique Cadilhac, Associate Professor Natasha Lannin
<b>Submission date</b>	31 March 2014
<b>AuSCR role</b>	Survey and data linkage
<b>Approved</b>	5 June 2014
<b>Status</b>	Completed
<b>Summary</b>	<p>Discharge planning following stroke is often sub-optimal and most patients feel little control over their discharge process. Patients discharged to the community and registered in the AuSCR in 2014 were sent a questionnaire (the PREPARED questionnaire) to assess the quality of their discharge care planning. Questionnaire data were linked to participants AuSCR data to identify factors associated with higher discharge quality scores and associations with outcomes such as quality of life. Our results highlighted the importance of monitoring the quality of discharge care planning and identified strategies that could be implemented within hospitals to improve discharge planning.</p>
<b>Outcomes</b>	<p>434 eligible registrants were sent questionnaires by the AuSCR office staff. We received 200 completed surveys (response rate 46%). The median age of participants was 72 (Quartile 1 [Q1], Quartile 3 [Q3]: 62, 79), 69% were male and 64% had ischaemic stroke. Non-responders (median age 71 [Q1, Q3: 61, 80] years, 61% male and 65% ischaemic stroke) were similar to responders. Only 18% of participants received all measured aspects of discharge care planning (i.e. achieved an overall PREPARED score of 100%). Of those that needed support services only 40% reported receiving assistance with organising equipment and 54% with organising community services.</p> <p>Those with quality scores less than 80% were more likely to report having pain (49% vs 35%, <math>p=0.04</math>) or anxiety or depression (49% vs 29%, <math>p=0.005</math>) at median three months post-stroke (Table 1). They were also more likely to report having unmet needs in these areas at approximately six months post-stroke.</p> <p>From our multivariable analyses, receiving stroke specific information developed by the local hospital was independently associated with discharge quality scores above 80% (OR: 5.7, 95%CI: 2.7, 12.4), as was referral to a local stroke support group (OR: 2.5, 95%CI: 1.1, 5.9). Those who achieved quality scores above 80% compared to those who did not, reported a statistically and clinically significant 10% increase in the EQ-5D quality of life utility score (Coefficient: 0.1, 95%CI: 0.04, 0.2) at three months. This group also had a lower incidence of unmet needs (IRR: 0.5, 95%CI: 0.3, 0.7) at six months following stroke.</p> <p>Our results highlight the importance of measuring the quality of discharge care planning and have identified potential areas for improvement than can be easily implemented within the hospital system.</p>
<b>Publications</b>	<ol style="list-style-type: none"> <li>1. Andrew NE, Kilkenny MF, Lannin NA, Cadilhac D. Patient and system factors associated with the quality of discharge planning from the acute care setting. <i>International Journal of Stroke</i> 2015 10(S3): 29</li> <li>2. Andrew NE, Busingye D, Lannin NA, Cadilhac DA. The quality of discharge care planning in acute stroke care: influencing factors and association with post-discharge outcomes. (under editorial review)</li> </ol>

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Exploring hospital and early discharge factors associated with long-term needs of stroke survivors and their carers</b>
<b>Principle investigator</b>	Dr Nadine Andrew
<b>Institute</b>	Stroke and Ageing Research Centre, Monash University
<b>Co-investigators</b>	Associate Professor Dominique Cadilhac
<b>Submission date</b>	26 June 2013
<b>AuSCR role</b>	Survey and data linkage
<b>Approved</b>	17 October 2013
<b>Status</b>	Completed
<b>Summary</b>	<p>We linked two existing sources of stroke data, the Australian Stroke Survivor and Carer Needs Assessment Project and AuSCR data. The linked data were used, to investigate the association between quality of life at 90-180 days following stroke and long-term unmet needs (median 2 years). Using multivariable regression we demonstrated a strong inverse association between quality of life at 90-180 days post-stroke and the likelihood of experiencing unmet needs at a median of 2-year. This work demonstrated the ability to use routinely collected quality of life data to identify those most at risk of long-term unmet needs.</p>
<b>Outcomes</b>	<p>A total of 602 surveys were sent to AuSCR registrants as part of the Needs Survey recruitment strategy. From these, 173 (29%) completed surveys were returned between March and August 2012. De-identified data from the two datasets were merged by the investigator using project ID numbers. Using multivariable analysis we found a strong association between the EQ-5D quality of life scores (0-100 rating; higher score=better quality of life) and the number of reported unmet needs at a median of two years [irr: 0.98, (95%CI: 0.97, 0.99) <math>p &lt; 0.001</math>]. For every one point decrease in a survivors quality of life score there was a significant likelihood of them having a 2% increase in the number of unmet needs reported.</p> <p>A significantly greater proportion of those who reported having problems with mobility, self-care and usual activities between 90 and 180 days reported having long-term unmet needs in multiple domains. However, those who reported having pain or anxiety/depression between 90 and 180 days following stroke were less likely to report having unmet needs at a median of 2-years following stroke for most unmet need domains. Having difficulty with usual activities between 90 and 180 days had the strongest positive association with long-term unmet needs (aOR: 4.5, 95%CI: 1.1, 7.3).</p> <p>We demonstrated that routinely collected HRQoL data can be used to identify survivors at risk of experiencing long-term unmet needs. This information is important for targeting service delivery to optimise outcomes following stroke.</p>
<b>Publications</b>	Andrew NA, Kilkenny MF, Lannin EA, Lalor E, and Cadilhac DA. Is health related quality of life between 90 and 180 days following stroke associated with long-term unmet needs? Qual Life Res. 2016 Aug;25(8):2053-62



## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Secondary prevention in stroke</b>
<b>Principle investigator</b>	Dr Stacey Jankelowitz
<b>Institute</b>	The George Institute for Global Health
<b>Co-investigators</b>	Professor Craig Anderson
<b>Submission date</b>	2011
<b>AuSCR role</b>	Survey
<b>Approved</b>	21 May 2012
<b>Status</b>	Completed
<b>Summary</b>	This project implemented changes to improve rates of secondary prevention in stroke through the prescription of antithrombotic, antihypertensive and lipid-lowering medications at discharge.
<b>Outcomes</b>	The intervention was effective in increasing discharge rates of secondary prevention in patients admitted with strokes. Longterm compliance was better in metropolitan than regional areas and may have been affected by GP knowledge.
<b>Publications</b>	Jankelowitz SK, Anderson C, Implementation of clinical guidelines for secondary prevention of stroke, Int J Stroke. 2015 Jun; 10(4); E37 doi: 10.1111/ij.s.12447.

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Fabry disease in stroke screening study</b>
<b>Principle investigator</b>	Professor Craig Anderson
<b>Institute</b>	The George Institute for Global Health
<b>Co-investigators</b>	Associate Professor Mark Parsons
<b>Submission date</b>	11 July 2011
<b>AuSCR role</b>	Participant recruitment
<b>Approved</b>	16 January 2012
<b>Status</b>	Project abandoned
<b>Summary</b>	A prospective, hospital-based, register study undertaken by lead clinicians in hospital sites registered in AuSCR. A novel simple screening test for Fabry disease was developed using dried blood spots on filter paper (DBS) for measuring $\alpha$ -galactosidase A activity. The Neurogenetics DNA Diagnostic Laboratory (headed by Dr Katherine Sims) at Massachusetts General Hospital (MGH) in Boston, United States (US) provides a rapid screening service for Fabry disease using the DBS sent via an envelope in regular post from sites anywhere in Australia. The test can be undertaken with high sensitivity and specificity within 1-2 weeks of collection at low cost. Genzyme Australia provided an unconditional research grant for: project coordination – one off payment; all DBS blood testing materials, postage and testing, and; development of the Fabry data sub-set off the AuSCR data spine
<b>Outcomes</b>	The project was abandoned in Dec 2013 after several attempts to obtain the reliable assay back from the US despite multiple supports from Genzyme at the US office.
<b>Publications</b>	Not applicable

## AuSCR Research Task Group approved projects

<b>Title</b>	<b>Australian stroke survivor and carer needs assessment</b>
<b>Principle investigator</b>	Associate Professor Dominique Cadilhac
<b>Institute</b>	The Florey Institute of Neuroscience and Mental Health/ Stroke and Ageing Research Centre, Monash University
<b>Co-investigators</b>	Ms Monique Kilkenny, Dr Nadine Andrew, Ms Rebecca Naylor, Ms Jacqui McKenzie
<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>1. Andrew NE, Kilkenny M, Naylor R, Purvis T, Lalor E, Moloczij N, Cadilhac DA. Understanding long-term unmet needs in Australian survivors of stroke. <i>Int J 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>2. Andrew NE, Kilkenny MF, Naylor R, Purvis T, Cadilhac DA. The relationship between caregiver impacts and the unmet needs of survivors of stroke, <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>3. Andrew NE, Kilkenny MF, NA Lannin, E Lalor, and Cadilhac DA. Is health related quality of life between 90 and 180 days following stroke associated with long-term unmet needs? <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>