



strokefoundation

National Stroke Foundation

National Action Plan for Stroke

Stop stroke. Save lives. End suffering.
www.strokefoundation.com.au



About the National Stroke Foundation

The National Stroke Foundation is a national not-for-profit organisation that works with stroke survivors, carers, health professionals, government and the public to reduce the impact of stroke on the Australian community. Our mission is to stop stroke, save lives and end suffering. We are the voice of stroke in Australia.

We will achieve this by:

- Raising awareness about the risk factors and signs of stroke and promoting healthy lifestyles.
- Improving treatment for stroke to save lives and reduce disability.
- Improving life after stroke for stroke survivors.
- Encouraging and facilitating stroke research.
- Advocating for improved stroke prevention, treatment and support.
- Raising funds from the community, corporate sector and government to continue our mission.

Visit www.strokefoundation.com.au for more information.

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- National Stroke Foundation Consumer Council.
- National Stroke Foundation Clinical Council.
- Attendees at national stroke survivor and carer forums held June-August 2012.
- Attendees at the inaugural Australian Stroke Survivor and Carer Summit, Canberra, 2012.
- Stroke Support Groups.
- Respondents to the National Stroke Survivor Survey of Unmet Need.

Australian Stroke Coalition

The Australian Stroke Coalition (ASC) was established in 2008. It is an alliance of organisations and groups galvanised by their common mission to improve stroke care, reduce duplication amongst groups and strengthen the voice for stroke care at a national and state level. The following members have endorsed the National Action Plan for Stroke.





The National Stroke Foundation has produced this document to outline proposed policy solutions that will improve the lives of Australians who are at risk of or who suffer from a stroke.

The document has been produced in consultation with stroke survivors and carers to address significant concerns about gaps in stroke services and support in Australia. It also has input from health professionals who are experts in stroke care.

It comes following consultation with stroke survivors and carers about the issues they face that were presented in forums across Australia and at the first Australian Stroke Survivor and Carer Summit in Canberra in October 2012.

Stroke survivors and carers presented a Stroke Call to Action document to Australian political leaders at a series of meetings held during the Stroke Summit. This policy document represents the solutions needed to address the significant gaps in stroke services and support that are captured in the Call to Action.

Stroke is Australia's second biggest killer and a leading cause of disability. It kills more men than prostate cancer and more women than breast cancer. An estimated 420,000 people live with stroke in Australia and this is projected to rise to over 700,000 people by 2032. The disease costs the Australian economy \$5 billion¹ a year.

Despite this there has never been federal budget funding for the implementation of a comprehensive stroke strategy – even though stroke has been an Australian National Health Priority Area since 1996.

The Australian stroke community is united in calling for this to change.

Calls to Action

The following Calls to Action were developed by stroke survivors and carers following a series of forums around Australia to discuss the state of Australian stroke care. They represent the needs of stroke survivors and carers and are the basis of a call for change in the way stroke is managed in Australia.

Consumer Call to Action 1

We need the ability to better understand our risk of stroke and what we can do to reduce our chances of having one. This includes more information in the community and from our doctor about what stroke is, the impact it can have, our risk and our risk factors and options and treatments available to help us lower our risk.

Consumer Call to Action 2

We need everyone who has a stroke to know what is happening to them as quickly as possible. This includes being able to recognise the stroke and know what action to take as well as being seen by health professionals who can quickly determine what is happening and explain this in easy to understand language.

Consumer Call to Action 3

In hospital we need a team treating us that knows about stroke and can make sure we get the right treatment quickly. This team should be able to give us the information and support we need as we adjust to such a life changing event.

Consumer Call to Action 4

We need rehabilitation that addresses our personal goals and includes us in decision making. We need opportunities for regular review of our potential for rehabilitation. When formal rehabilitation is no longer appropriate or available we want to drive our own recovery and need the support and tools to do so.

Consumer Call to Action 5

When we go home from hospital we need to feel we are ready to face life after stroke. Our fears and our concerns need to be addressed and we need information about where we can go and who we can call for help to face the challenges we know are ahead of us.

Consumer Call to Action 6

When we go home we need help to adjust to life after stroke, to find the right people and services in the community to help us with our recovery and to enable us to drive our own recovery. This needs people to better understand the disabilities associated with stroke. Many of us will need additional support in this adjustment and help in other areas. For example, return to work and financial assistance.

Consumer Call to Action 7

We need emotional and psychological support at every step of our journey. It needs to be offered to all of us. This support can take many forms and may not always be provided by the health system.

Consumer Call to Action 8

We need regular updates and information on what has happened to us and on our progress, at every stage of the journey starting immediately. We need to be included in decisions about our recovery rather than simply being told what will happen.

Proposed stroke improvement program

We are proposing the Australian Government provide \$198m in funding over three years for a comprehensive Australian Stroke Improvement Program. If adopted the Stroke Improvement Program will result in significant improvements to the way stroke is managed in Australia.

As a package of measures these policy solutions will deliver an improved stroke management framework with:

- Higher community awareness about stroke leading to faster diagnosis and treatment.
- Better detection and management of community health risk with lower incidences of stroke and other major diseases.
- Improved standards of stroke care resulting in fewer deaths and lower levels of disability.
- A comprehensive approach to caring for and supporting stroke survivors as they recover in the community.
- Significant costs savings to the Australian public.

All the proposals within this policy document are based on evidence, reviewed and summarised in *NHMRC Clinical Guidelines*. Information and inspiration has also been drawn from stroke care reform in the UK – specifically in London where highly cost effective changes to stroke care and management were implemented with significant reduction in morbidity and mortality and associated cost savings.

Australian Health Reform Process

This set of policy proposals has been developed within the context of significant ongoing national health reform in Australia. It is important to note the breadth of the stroke burden in Australia is such that it spans the entire Australian health system from prevention to primary care, to the hospital system, rehabilitation, disability, community health services and aged care. Therefore, reform elements such as the proposed National Disability Insurance Scheme and Aged Care Reform as well as the broader national health care reforms including movement to Activity Based Funding for hospital services, the introduction of Local Hospital Networks and Medicare Locals and shared state and federal hospital growth costs are directly relevant to many of these policy solutions.

These policy proposals have been developed to fit within the existing and proposed reform processes where possible but we do acknowledge that given the ongoing nature of many of these reforms further discussion is likely to be required to fine tune these proposals within the reform context.

UK Reform: What did they do?

In 2007 the British Health Secretary, Alan Johnson MP, launched a National Stroke Strategy designed to improve stroke services in England. The ten year strategy included a Ten-Point Plan for Action (see Table 1).

Table 1: UK Ten-Point Plan for Action

1. Awareness: improve public and professional awareness of stroke symptoms.	2. Preventing stroke: supporting healthier lifestyles and taking action to tackle vascular risk.
3. Involvement: are people with stroke informed partners in their care planning?	4. Acting on the warnings: TIAs are a clear warning sign that a further stroke may occur.
5. Stroke as a medical emergency: getting people to the right hospital quickly.	6. Stroke unit quality: stroke unit care is the single biggest factor that can improve a person's outcomes following a stroke.
7. Rehabilitation and community support: intensive rehabilitation immediately after stroke.	8. Participation: assistance to overcome physical, communication and psychological barriers.
9. Workforce: people with stroke need to be treated by a skilled and competent workforce.	10. Service improvement: stroke care demands services working together in networks, looking across all aspects of the care pathway.

In his forwarding remarks to the document, Mr Johnson noted that tremendous advances in medical knowledge of the brain and technological ability provided significant opportunities for saving lives and reducing disability. Morally, these advances demand that we treat stroke as the next major challenge for the National Health Service (NHS). He noted: "We now need to move from this gradual evolution to a comprehensive revolution".

Five years in to the ten-year plan assessment of stroke care in London, where the major focus of stroke improvement has been, has shown significant success including:

- Increasing the proportion of patients spending more than 90% in-patient stay on a stroke unit from 39% in Q1 2008-09 to a high of 83% in Q3 2011-12.

- Reducing the average length of stay in hospital from 18 days in 2004 to just ten days in 2010.
- 30 day mortality reducing from around 24% in 2004 to around 16% in 2010.
- Within six months of centralising stroke care in London in 2010, 14% of stroke patients taken to a London Hyper Acute Stroke Unit (HASU) had been given thrombolysis. This is compared to only 3.5% of patients in the same six month period the previous year.
- A \$3.5 million reduction in direct costs over the first 90 days as a result of implementing improved access to proven acute therapies via this model.

Australian Stroke Improvement Program at a glance

Policy proposal	Budget impact
<p>1. Empowering Australians to identify and manage their health risk.</p> <ul style="list-style-type: none"> • <i>Know your numbers</i> health check program. • Health check restructure to create a single integrated health check. • Consumer education and self-management tools. 	<p>\$16.5m over three years.</p> <p>Proposed health check restructure could result in budget savings. Extra cost may come with increased patronage of health checks but offset by benefits from overall reduction in serious health events.</p>
<p>2. Increasing the number of Australians eligible to receive time-critical stroke treatment.</p> <ul style="list-style-type: none"> • FAST – the signs of stroke social marketing campaign. 	<p>\$6.5m over three years.</p>
<p>3. Delivering world-best standard stroke care to all Australians.</p> <ul style="list-style-type: none"> • More and better stroke units. • Improved stroke unit access. • Integrated data collection and quality improvement efforts. 	<p>\$121m over three years.</p>
<p>4. Providing care and support stroke survivors need to adjust to life after stroke.</p> <ul style="list-style-type: none"> • StrokeConnect, stroke survivor follow-up and service-linking program. • Information and support. • Carer training. • Improved self-management. 	<p>\$21m over three years.</p>
<p>5. Facilitating research to develop the best ways to aid rehabilitation efforts and ensure adequate emotional and psychological support for stroke survivors.</p> <ul style="list-style-type: none"> • Stroke Research Network. • Dedicated stroke research funding. 	<p>\$33m over three years.</p>
<p>Total:</p>	<p>\$198m over 3 years</p>

1. Empowering Australians to identify and manage their health risk

\$16.5m over three years

What is the problem?

Too many Australians are unaware of their personal risk factors for diseases such as stroke and heart disease (collectively known as cardiovascular disease or CVD), type 2 diabetes and chronic kidney disease and are not empowered to self-manage their risk. Furthermore, there is currently no integrated system for detecting, assessing or managing risk of vascular and related diseases within the Australian health system.

A coordinated approach is required to increase awareness of individual vascular and related disease risk, to provide high quality assessment of individual risk and to provide appropriate interventions to support risk management. There must be a commitment underpinning the approach to supporting consumers to improve their health literacy and to increase their capacity to self manage and actively reduce their health risk.

CVD is Australia's biggest killer causing more than 46,000 deaths each year - just over a third of total mortality - and afflicting 3.5 million adults.² It accounts for 16% of the overall burden of death and disease in Australia and is the most expensive disease group in terms of direct healthcare costs, at \$6 billion a year or 11% of recurrent expenditure.³

CVD has a strong relationship with type 2 diabetes and chronic kidney disease. Because they share risk factors, underlying causes and disease mechanisms, stroke, heart and vascular diseases often occur together with diabetes and chronic kidney disease. For example, it is estimated over 400,000 Australians have both CVD and diabetes. Thus, effective prevention and management of one condition can lead to reduction in the risk of related diseases.⁴

Modifiable risk factors for CVD and related diseases include tobacco smoking, high blood pressure, high blood cholesterol, insufficient physical activity, overweight and obesity, poor nutrition and type 2 diabetes. Atrial fibrillation (irregular heartbeat), transient ischaemic attack and a high intake of alcohol also increase the risk of stroke.⁵

Risk factors for stroke and other CVD are often clustered together and having more than one risk factor can magnify the risk of disease.⁶ The National Stroke Foundation has, therefore, been at the forefront of efforts to promote an absolute risk approach to CVD risk reduction that takes into account each individual's overall risk profile.

Recent data shows while some risk factors such as smoking and alcohol consumption are coming down in Australia there are other risk factors not being managed well.

The Australian Health Survey shows in 2011-12, 63.4% of Australians aged 18 years and over were overweight or obese – an increase from 61.2% in 2007-08 and 56.3% in 1995. 60.3% of men aged 18 years and over had a waist circumference that put them at an increased risk of developing chronic disease, while 66.6% of women had an increased level of risk.⁷

The Survey also shows in 2011-12, just over 3.1 million people (21.5%) aged 18 years and over had measured high blood pressure (systolic or diastolic blood pressure equal to or greater than 140/90 mmHg).⁸

The recently released Victorian Health Monitor report has shown high rates of hypertension within higher CVD risk age groups: 29.7% of 45-54 year olds; 44.6% of 55-64 year olds; and 64% of 65-75 year olds.

This report also identified alarming proportions of untreated hypertension amongst Victorian men with more than 1-in-5 45-64 year olds and almost 1-in-3 65-75 year olds not managing their hypertension (Data: 45-54: 22.7%, 55-64: men 20.3%, 65-75: 27.7%).

Identification of risk and action to modify these risk factors has significant potential to reduce the number of CVD events occurring each year and reduce incidence of diabetes and chronic kidney disease and yet current Australian Government funded health checks are not identifying those at risk primarily because of low access rates, non-integrated approaches to CVD risk assessment and the absence of a national program to support better management of risks for CVD and related diseases like type 2 diabetes and kidney disease. Less than a quarter of those over 75 years and only 6% of those aged 45-49 are accessing regular health checks.⁹ Given the proportion of overweight, obese and hypertensive people in the community these figures are alarming.

The Australian Institute of Health and Welfare published a framework for monitoring the prevention of vascular and related disease in 2009.¹⁰ This Framework highlighted evidence showing existing vascular and related disease assessment and management programs have limited uptake and are not well integrated or promoted as part of a national preventative health system.

What should be done?

In line with recommendations from the National Vascular Disease Prevention Alliance we believe there are three key stages required to empower Australians to better understand, manage and improve their disease risk.

1. Raise individual awareness of disease risk

Firstly, the Australian Government must act to improve the detection of risk of vascular and related disease in the adult population aged 45 years and over by increasing individual awareness of risk status.

There is a need for quality controlled and evaluated activities to increase identification of potentially at-risk individuals and refer these people to general practice for more comprehensive assessment and follow up.

A system of proactive checks in primary care and in other community settings, such as community health centres, pharmacies and workplaces, is required to maximise population reach and reduce inequalities in access.

Appropriate activities range from awareness raising of risk factors through to undertaking preliminary risk awareness and early identification activities such as blood pressure measurements or using the AusDrisk assessment tool.

Unlike screening programs, such as those for breast and colorectal cancers, a program of this type would not provide a screening test. Rather it would aim to increase an individual's awareness of risk through consideration of individual risk factor status and prompt more thorough ongoing risk assessment and risk management.

Individuals would be provided with tailored advice about what they can do to reduce their personal risk of vascular and related disease. Subsequent action would entail a combination of lifestyle advice and access to related programs and, when necessary, further assessment.

2. Provide high quality assessment of individual risk

The second step is provision of high quality assessment of individual vascular and related disease risk by collecting data on major risk factors through simple questions, tests and measurements considered in the context of risk for CVD, diabetes and kidney disease.

The primary care setting, including that of general practice and Aboriginal Medical Services, is the appropriate one for undertaking comprehensive vascular and related disease risk assessments and delivering ongoing preventative care for those people identified to be at higher risk. Assessment may be undertaken by a General Practitioner (GP) or by a practice nurse working with a GP and with protocols.

Assessment in the general practice setting should be undertaken amongst those referred through the community based settings but could also be initiated by the GP or practice nurse on visits for other matters. Ongoing preventative care may be provided by the relevant team of medical, nursing and allied health professionals in the primary care and other community settings.

The assessment should include recognised measures to assess risk including:

- A CVD risk assessment (an absolute risk assessment where appropriate and consideration as high risk if clinically indicated).
- AUSDRISK (+/- blood glucose tests).
- Serum creatinine and urinary albumin.

3. Provide quality assured lifestyle and medical interventions

Assessment and classification of moderate and high-risk individuals should result in provision of medical interventions to reduce individual risk and referral to quality-assured lifestyle modification programs. GP's would prescribe necessary medication and refer people at risk to lifestyle interventions which could be delivered through a range of community settings.

Medical interventions could include drug treatments for high blood pressure and high blood cholesterol.

Principal evidence-based lifestyle interventions could include: smoking cessation services; weight management or exercise and behaviour change programs. Lifestyle modification programs incorporating weight reduction, healthy eating and physical activity (eg. Life! In Victoria, Get Healthy in NSW) are currently available for people at high risk of type 2 diabetes and could be broadened to include people who may be at increased risk of vascular diseases. Establishment of a systematic process for identification of risk of CVD, diabetes and kidney disease will increase referrals to such programs increasing their efficiency.

There is also scope to develop and introduce new tools designed to assist consumers to better understand their risk and involve them in the process of decision making about treatment and care.

Decision aids are an example of a tool used by health practitioners to involve patients in the decision making process about things such as potential medical treatment and lifestyle modification. Ranging from story board style tools to increasingly sophisticated Smartphone technology, decision aids are demonstrating potential to be a useful and effective communication tool.

The use of decision aids with patients has been shown to significantly increase knowledge as well as accuracy of risk perception.¹¹ Patients are reported to have greater satisfaction with the decision making process, have more realistic expectations and are more likely to be decisive with fewer patients left undecided about their treatment.¹²

As a specific example, for patients with atrial fibrillation who had participated in a major clinical trial, the use of an audiobooklet improved their understanding of the benefits and risks associated with different treatment options and helped them make definitive choices about therapies.¹³

To quote from a literature review on shared decision making and decision aids: “better aids are those in which the information is personalised to the individual patient. Therefore, web based or computer programs can have an advantage. They can be programmed to enhance interactivity and contain the potential for personalising information such as individual risk factors based on each patient’s risk profile”.^{14,15}

There is also potential for technology to be used in conjunction with the rollout of the e-health record.

Policy proposal	Action	Budget impact
Awareness Raising: helping individuals to identify they may be at risk.	<i>Know your numbers</i> community and pharmacy health check program.	\$15m over three years.
Comprehensive risk assessment in primary care.	Integrated Health Checks in primary care – consolidate existing MBS-funded health checks into a flexible standalone integrated health check using an absolute risk approach.	Restructure of existing health checks could result in budget savings through reduced duplication. Extra cost may come with increased patronage but offset by benefits from overall reduction in serious health events.
Management and follow up in primary care.	Treatment of at-risk patients and referral to existing programs and services.	Status quo.
Support for consumer tools such as decision aids.	Development of consumer education and self-management tools potentially including Smartphone technology.	\$1.5m over three years.

Policy proposal detail

Awareness Raising – *Know your numbers*

The *Know your numbers* program run by the National Stroke Foundation is a community and pharmacy based health check program looking at risk of heart disease, stroke and diabetes. An evidence-based intervention it has proven successful in enabling Australians at risk of chronic disease to better understand and take action to reduce their risk. By so doing, the program contributes to improvements in the identification and aversion of stroke and other CVD risk through early detection and appropriate assessment and management.

The Stroke Foundation has run *Know your numbers* since 2007 and results demonstrate a comprehensive national service can be provided. Program numbers to date have proven:

- For every 100,000 people checked at a pressure station, more than 18,000 will visit their GP.
- For every 100,000 people checked at a pressure station, between 57 and 191 strokes can be averted (depending on treatment levels).

Data collected to evaluate the effectiveness of *Know your numbers* and to inform ongoing program improvement has demonstrated:

- In 2011, 47% of participants checked registered a high blood pressure reading and 50% were at high risk of developing Type 2 diabetes in the next five years. Of those, 70% were referred to their GP for further assessment.
- Among participants who were 'at risk', almost 20% had an AUSDRISK score of 20+ indicating a one in three chance of type 2 diabetes within the next five years.
- Among those identified as 'high risk', 69% didn't know they were at risk of diabetes.

A three-month follow up of participants in *Know your numbers* showed increased knowledge about the health risk of high blood pressure and 100% of follow up participants reported at least one action to address their health:

- Around 1 in 10 stopped or reduced smoking.
- Almost 30% had lost weight.

- Nearly 40% increased vegetable and fruit consumption and a similar number reduced salt intake.
- More than half were checking their blood pressure regularly.

The program directly supports desired Australian Government healthcare outcomes including early detection, management and prevention of chronic diseases. The *Know your numbers* program also supports and helps to leverage the Pharmacy Guild of Australia Quality Assurance Program (QCPP). By partnering in the delivery of *Know your numbers* health checks, community pharmacy is able to meet its community service obligations under the Fifth Pharmacy Agreement, thereby increasing the efficiency of existing government investment.

The National Stroke Foundation is currently delivering *Know your numbers* with the support of state governments in New South Wales and Queensland. It is recommended the Australian government provide funding to rollout the program to all states and territories delivering an intensive month long campaign through partnership with community pharmacies and in other community settings.

Fully funded, the *Know your numbers* program has the potential to check 570,000 people per annum, referring 105,000 people to GPs for full health assessments and averting between 325 and 1,089 strokes each year¹⁶ as well as additional events associated with diabetes, heart disease and kidney disease.

The proposed option presents a low risk, cost effective model that delivers significant outcomes for the Australian community with a cost offset of between \$22.2million and \$74 million.¹⁷ This is a conservative estimate as it includes only the cost offsets associated with stroke and not savings associated with other forms of CVD.

Comprehensive risk assessment in primary care

In order to maximise the benefit of the *Know your numbers* program there needs to be an overhaul of the Australian health check system.

Specifically, the Australian Government should consolidate the existing disparate group of health checks funded through MBS to create one integrated health check using an absolute risk approach.

The primary care system is delivering a rising number of health checks in the adult population but the overall uptake remains low. There is also no integrated system for detecting, assessing or managing risk of vascular and related diseases.¹⁸

Table 2: Risk assessment opportunities provided by Medicare – description and demand (Australian Institute of Health & Welfare, 2009).

Check	Number of checks 2008/09	% of eligible population 2008/09
Aboriginal and Torres Strait Islander (ATSI) adult health check.	18,000	6.1%
Type 2 diabetes risk evaluation.	11,000	0.4%
45-year-old health check	200,000	6.7%
Older persons health assessment	310,000 (non ATSI) 5,200 (ATSI)	22.9% (non ATSI) 13.1% (ATSI)

Because of the shared risk factors and co-morbidities that exist between CVD and related diseases there is strong rationale for introduction of an integrated health check in place of the existing disease, age group and ATSI specific health checks.

Consolidation of health checks would improve efficiency in data collection and support efforts to improve management and follow up.

Management and follow up in primary care

This aspect of the proposal involves maintaining existing lifestyle and medical interventions to reduce individual risk including referral to existing programs and provision of medication to manage risk factors.

Support for consumer risk self-management

We recommend government investment in development of specific consumer education tools and programs to support consumers to better understand their individual risk and to manage known risk factors. There are a range of potential tools including health related Smartphone applications that have been shown to improve self-management capacity and ultimately better health outcomes.

2. Increasing the number of Australians eligible to receive time-critical stroke treatment

\$6.5m over three years

What is the problem?

Stroke is a time-critical illness and faster diagnosis and treatment saves lives and quality of life. At present not enough people recognise a stroke when it occurs and too few know how vital it is to call ambulance.

It is critical stroke is diagnosed and treated quickly as the effectiveness of many treatments is dependent upon the time between onset of symptoms and intervention to minimise brain damage. The sooner stroke patients get to hospital the lower the likelihood death or permanent disability will result.

Time dependent treatments that reduce death and disability after stroke include:

- access to stroke unit care in a hospital;
- aspirin as soon as possible after ischaemic stroke; and
- use of a tissue plasminogen activator (tPA), a thrombolytic or clot-busting drug, which is most effective when given very early but cannot be administered more than 4.5 hours after a stroke.

Failure to act when symptoms arise is the main factor behind stroke treatment delay, accounting for around 68% of the total delay in time to admission for ischaemic stroke.¹⁹

Many people in Australia are unable to act because they cannot recognise the symptoms of stroke when it occurs. Currently, one in five people cannot recognise any signs of stroke and only a third of people can recognise three or more signs.²⁰

Additionally, many people with transient signs of stroke (transient ischaemic attack or TIA) do not act as symptoms seemingly resolve themselves. And yet up to 20% of patients having a TIA go on to subsequent stroke within 90 days^{21,22} if early preventative treatment is not instituted.

Half of those who experience stroke symptoms delay calling an ambulance; many individuals hope symptoms will alleviate; or will elect to speak to friends, family or their GP.²³ As a result only 41% of patients present at hospital within time for potentially life-saving treatment.²³

Importantly, only 7% of patients eligible for clot-busting treatment receive it.²⁵

What should be done?

Since 2007 the National Stroke Foundation has been successful in raising awareness of the signs of stroke by promoting the FAST test through social marketing campaign activity.

The central feature of the campaign, run with state government support in Victoria, is mass media advertising using a pre-existing television commercial and associated print, radio and online promotion. Most recently the campaign has featured a locally adapted version of the successful UK Fire in the Brain advertisement with associated campaign material.

There is a recognised need for further local adaptation of this campaign to incorporate messages which highlight the need for action even if symptoms are transient. This work will ensure the campaign remains relevant to emerging stroke issues and continues to be a proven success in educating people about stroke signs in Australia.

The FAST test is an easy way to remember and recognise the signs of stroke. FAST stands for Face, Arms, Speech and Time to act. Using the FAST test involves asking these simple questions:

Face – Check their face. Has their mouth drooped?

Arms – Can they lift both arms?

Speech – Is their speech slurred? Do they understand you?

Time – Is critical. If you see any of these signs call 000 straight away.

Evaluation of the program demonstrates that FAST increases community awareness of stroke signs in all areas where it is delivered. In Victoria, where state government funding has been provided for the program since 2007, awareness of the signs of stroke is the highest in the country. Furthermore, independent analysis of Melbourne ambulance data has identified increased dispatches for stroke in the month following each FAST campaign push, demonstrating the 'call 000' message gets through.

There is a social and economic benefit to be derived from increased awareness of stroke signs.

Better awareness means more people getting to hospital in time for life saving treatment and ultimately less death and disability from stroke.

An updated systematic review and meta-analysis published in *The Lancet* has found for every 1000 patients who receive thrombolysis treatment within three hours of stroke,

about 100 more will survive alive and independent than for 1000 patients not thrombolysed. For patients thrombolysed within six hours of stroke about 40 more will be alive and independent than if they had not received treatment.²⁶

Even when the effects of tPA are excluded admission to a stroke unit within three hours after symptom onset resulted in better outcomes three months later than those admitted after the first six hours. For every 1000 people being admitted early 60 people avoid death and dependency.²⁷

There are also cost savings that result from quicker access to stroke treatment.

Previous analysis nationwide has estimated increasing access to tPA from 3% to 20% within 4.5 hours among patients that have had an ischaemic stroke would mean 300 additional patients each year would leave hospital alive and independent.²⁸

Policy proposal	Action	Budget impact
Increase Australian knowledge of the signs of stroke to improve hospital presentation times and increase access to life saving stroke treatment.	Delivery of FAST social marketing campaign including Fire in the Brain TVC and work to modify the campaign to highlight the importance of action even if stroke symptoms are transient.	\$6.5m over three years.

Policy proposal detail

It is recommended the Australian Government commit \$2m per annum over three years to support delivery of the FAST message to all Australians via a coordinated social marketing campaign.

The campaign would consist of television, print, radio and internet advertising targeted primarily at the high stroke risk population – Australians aged over 50 years – while a secondary target audience is those aged 40-54 years who are often carers and bystanders when stroke occurs.

This contribution from the Australian Government would ensure the FAST message was broadcast to a targeted Australian audience. The activity – including advertising,

provision of online information and education tools and distribution of FAST collateral – would result in improved awareness about the signs of stroke and increased dispatches of ambulances for stroke. This will ensure health outcomes for stroke patients are improved and death and disability is reduced.

It is also recommended \$0.5 million be provided for further adaptation of the FAST campaign material to include specific messaging for transient stroke.

By increasing access to time critical treatments the FAST program has the potential to avoid at least 300 instances of death and disability from stroke in Australia each year.

3. Delivering world-best standard stroke care to all Australians

\$121m over three years

What is the problem?

Australians deserve nothing less than world-best standard stroke care. This is not currently occurring.

This proposal calls for the following outcomes:

- Stroke units established in every hospital with over 100 stroke admissions per year.
- Sufficient capacity within stroke units to ensure access for all stroke patients in each local health network's catchment area. This includes meeting the shortfall of stroke specialists in medicine, nursing and allied health.
- Adoption of strategies to ensure all Australians are treated on a stroke unit including hospital payment incentives to improve stroke care quality and strategies to improve care in remote and regional areas (e.g. rural coordinators, telemedicine, models for transfer).
- Support for health system data collection to aid assessment efforts including ongoing assessment of Australian stroke care standards.
- Ongoing quality improvement programs to build and maintain world-best standard including high quality education and training programs for stroke care professionals.

There are a number of interventions recommended in the National Health and Medical Research Council (NHMRC) approved *Clinical Guidelines for Stroke Management 2010*²⁹ that are proven to reduce death and disability after stroke. These include:

- **Stroke unit care:** Overwhelming evidence (31 clinical trials) has shown immediate clinical care within a specialised stroke unit significantly reduces death and disability after stroke compared with care in general wards for all people with stroke. For every 1000 people treated on a stroke unit a further 60 people are saved from death and/or disability than those treated elsewhere in a hospital.³⁰

- **Thrombolysis:** For every 1000 patients who receive thrombolysis treatment within three hours of stroke, about 100 more will survive alive and independent than for 1000 patients not thrombolysed. For patients thrombolysed within six hours of stroke, about 40 more will be alive and independent than if they had not received treatment.³¹
- **Antiplatelet therapy:** Antiplatelet therapy has been found to reduce death and disability when taken within 48 hours (12 Randomised Control Trials or RCTs) or within the first few months (21 RCTs) and continued long term. For every 100 people treated on with antiplatelet therapy within 48 hours, two people are saved from death and/or disability.^{32,33}
- **Blood pressure-lowering medications:** A systematic review (10 RCTs) found therapy to lower blood pressure (BP), even when initial BP was within normal range, reduced recurrent stroke and cardiovascular events in patients with a previous stroke or TIA.³⁴ For every 100 people treated with BP-lowering medication, three people are saved from death and/or disability from recurrent stroke and cardiovascular events.³⁵
- **Rehabilitation in the community:** A Cochrane review (14 RCTs) found treatment in rehabilitation therapy services in the community within the first year after stroke reduced the odds of a poor outcome. For every 100 people receiving rehabilitation in the community, six people are saved from death and/or disability.³⁶

The gap between the clinical care that is recommended in best-practice guidelines and what actually happens in the Australian healthcare system is resulting in increased costs and greater burden of disability associated with stroke. Providing better access to evidence-based stroke care would provide improved health benefits to individuals, carers and society as well as provide large potential cost offsets by reducing the resources required to provide stroke care.

National audits of the organisation of stroke care in over 300 acute and rehabilitation hospitals and clinical audits of stroke care provided to more than 14,000 patients over the past four years^{37,38,39,40,41} have demonstrated fundamental deficiencies. For example:

- 40% of patients do not receive their care in a dedicated stroke unit.⁴²
- Only 7% of patients receive thrombolysis.⁴³
- 20% of stroke patients are discharged from hospital without medication (cholesterol or blood pressure-lowering) to prevent recurrent stroke.
- Up to 70% of patients do not receive education relating to stroke (60% of carers were not offered training to better assist the person affected by stroke).
- Almost half of patients are put at risk of complications because they are given food or drink before their swallow ability is screened or assessed.
- Nearly 40% of hospitals did not provide routine assessment of the need for ongoing rehabilitation.
- 44% of hospital staff are denied access to a program of continuing education in stroke management.⁴⁴
- Incentivise provision of stroke services in-line with clinical guidelines and in support of identified Australian Safety and Quality Goals for Health Care.
- Monitor and measure the quality of stroke care delivered in the Australian health system.
- Support health service providers through quality improvement programs.
- Support health professionals to maintain high standards through access to quality training and education.

Establish stroke units

Evidence shows the fundamental platform for delivery of quality stroke care is a stroke unit. To quote from the UK Government's National Stroke Strategy, "stroke unit care is the single biggest factor that can improve a person's outcomes following a stroke".⁴⁶

Even when the effects of thrombolysis treatment are excluded, admission to a stroke unit within three hours after symptom onset resulted in better outcomes three months later than those admitted after the first six hours. For every 1000 people being admitted early, 60 people avoid death and dependency.⁴⁷

For this reason the National Stroke Foundation advocates for stroke units to be established in all hospitals with over 100 stroke admissions per year and yet we know as a result of our most recent hospital audit process that 16 hospitals⁴⁸ still don't meet this requirement.

The Australian Government must accept stroke care in this country continues to be sub-standard until all hospitals that need a stroke unit have one.

A stroke unit is a dedicated section of a hospital that includes clinicians who have stroke expertise, written stroke protocols for emergency services, acute care and rehabilitation, ability to offer thrombolytic therapy or protocols to transfer appropriate patients to a comprehensive stroke centre, timely neurovascular imaging, timely access to expert interpretation and coordinated processes for patient transition to ongoing rehabilitation and secondary prevention services.

There needs to be federal leadership to ensure gaps in stroke unit availability are closed.

Stroke survivors and their families are feeling the effects of poor care, living with avoidable disability or in some cases, not surviving their stroke. Their stories, relayed through the Call to Action, reinforce the knowledge that the gap between recommended and actual clinical care is resulting in increased costs and greater burden of disability associated with stroke.

Providing better access to evidence based stroke care would provide improved health benefits to individuals, carers and society as well as provide large potential cost offsets by reducing the resources required to provide stroke care. For example, increasing access to stroke units and thrombolysis is highly cost effective resulting in more than 9000 Disability-adjusted life years (DALYs) saved at a cost of \$376.53 per DALY.⁴⁵

What should be done?

The above statistics are damning and this policy proposal calls on the Australian Government to fund a national stroke care improvement strategy that will ensure all Australians have access to world-best standard stroke care through the Australian healthcare system.

To ensure Australian stroke care is able to meet world-best standards the National Stroke Foundation proposes that the federal government implement a quality improvement program to:

- Provide support for development of systems and processes to increase access to stroke units.

Improve access to new and existing stroke units

Establishing stroke units is the first step but there must also be a focus on improving access to stroke unit care. It is not acceptable for four-in-ten Australians who have a stroke to miss out on the quality of care a stroke unit provides.

Issues of access relate to geography but they also relate to resourcing and capacity of stroke units. Stroke survivors have advised us they have been unable to access stroke unit care because of a lack of beds or they were admitted to a stroke unit only to be moved into a regular ward too soon because the bed was required.

The Australian Government must support the healthcare system to improve access to stroke units by facilitating capacity development but also by encouraging development of innovative solutions to breakdown geographic barriers and open up the availability of stroke unit care to a much broader population.

Monitor and improve quality of stroke care

We won't know we are delivering world-best standard stroke care in Australia unless we have a comprehensive monitoring system that captures appropriate data by which to measure stroke care quality and adherence to evidenced-based guidelines. Likewise, we won't ever meet our ambition for world-best standard stroke care if we don't link our data collection systems to quality improvement programs across the stroke care system – acute and sub-acute or rehabilitation.

Unfortunately, there have been few programs implemented in Australia for monitoring quality of care. This has resulted in institutions, managers and clinicians having little awareness of how their services compare with others and with pre-determined standards.⁴⁹ The Australian Commission of Safety and Quality in Health Care likens the lack of systematic measurement of the quality of health services as analogous to attempting to monitor financial status in the absence of financial data.⁵⁰

International programs have successfully improved adherence to evidence based recommendations and improved clinical care by actively monitoring and measuring the quality of stroke care being provided through systematic data collection. Targeted support is then provided, where necessary, to improve quality of care and ensure evidence-based guidelines are adhered to.

Over the past decade much work has been undertaken to develop systems that will monitor and improve stroke care in Australia. More recent work has recognised the need to see these programs integrated and fully rolled out, particularly in sites admitting large numbers of stroke patients. These programs include:

- The National Stroke Foundation's National Stroke Audit Program: a program which is implemented annually in the acute and rehabilitation settings alternating every two years and collects a large amount of data measuring adherence to recommendations for multidisciplinary care outlined in the *National Clinical Guidelines for Stroke Management 2010*. Around 320 sites nationally participate in Audit program.
- The Australian Stroke Clinical Registry (AuSCR): a program run through a collaboration between the George Institute, the National Stroke Foundation, the National Stroke Research Institute and the Stroke Society of Australasia through which a minimum data set of four process indicators are collected on all patients in 26 sites nationally.
- The National Stroke Foundation's StrokeLink program which is available in 24 hospitals in Queensland where it is funded and has been acknowledged as a driver of improved quality of care.

Despite significant time and financial investment there is currently no overarching system that allows integration of these data sets. Thus these multiple and unlinked data collection processes not only have the potential to duplicate effort, give inconsistent results and possibly lead to confusion but are also limited because they are not linked to quality improvement activities.

This proposal calls on the Australian Government to take advantage of existing data collection and quality improvement programs that have been proven to work. By investing in these solutions the relevant data will be collected and specially tailored quality improvement programs will be put in place to ensure we can meet the bold but achievable aim of delivering world-best standard stroke care.

Policy proposal	Action	Budget impact
Strategy to ensure all Australians are treated on a stroke unit (SU).	Stroke Care Improvement Fund – competitive fund to support development of innovative systems and processes to increase stroke unit access and access to thrombolysis treatment including regional coordination, enhanced SU capacity and SU establishment in some locations. This should be supported through the introduction of stroke care performance incentives through Activity Based Funding of hospital services.	\$100m over three years.
Comprehensive integrated data collection and quality improvement.	Australian Stroke Clinical Registry, National Stroke Foundation Audit, Health Professional Education and Quality Improvement activities.	\$21m over three years.

Policy proposal detail

Stroke Care Improvement Fund to ensure all Australians are treated on a stroke unit

It is recommended the Australian Government establish a \$100m competitive Stroke Care Improvement Fund to enable eligible stroke service providers to deliver the following outcomes:

- Establishment of stroke units in all Australian hospitals admitting more than 100 stroke patients.
- Development and implementation of innovative processes and procedures to improve access to new and existing stroke units.
- Development and implementation of innovative systems to improve regional coordination (e.g. Telehealth, regional coordinators, models of care for transfer in and out etc).

Various models of stroke care and support are available to deliver the above outcomes so a competitive funding approach would encourage development of innovative, locally driven proposals that draw upon local expertise and result in solutions that meet local needs. It would also provide the ability to promote collaboration and

cooperation between service providers, including Local Hospital Networks and/or Medicare Locals, to develop cost-effective proposals to deliver stroke care improvements across broad geographic areas.

The \$100m Stroke Care Improvement Fund should be made available over three annual competitive grant funding rounds with general principles in line with that used by the recent Health and Hospitals Fund. Terms of reference for the fund should be developed by the Australian Government in consultation with the stroke community including state Stroke Clinical Networks, representatives of stroke survivors and carers, the Stroke Society of Australasia and the National Stroke Foundation.

The Government should also consider enhancing the outcomes of the Stroke Care Improvement Fund by introducing an incentive element to the Activity Based Funding model for hospital services. Use of incentive funding models to facilitate stroke unit care is already being explored in Western Australia and Queensland and would inform this thinking. Stroke is a prime candidate for performance incentive funding as there is industry consensus regarding what constitutes quality stroke care. This consensus resulted in stroke being one of the first disease groups to have Australian Safety and Quality Goals set by the Commission for Safety and Quality in Health Care.

Comprehensive integrated data collection and quality improvement

Data collection for stroke must be comprehensive and must be integrated to avoid duplication, inconsistency and confusion. In addition there must be a formal link made between collection and analysis of data and formal quality improvement measures.

Importantly, the integrated system of data collection and quality improvement to meet best practice care protocols must be applied to both acute and sub-acute or rehabilitation service provision.

It is proposed the Australian Government invest \$21m over three years to support data collection and quality improvement activities.

Data collection systems – National Stroke Audit and Australian Stroke Clinical Registry

Funding would support implementation and integration of existing data sets in the National Stroke Audit and the Australian Stroke Clinical Registry to ensure maximum efficiencies and quality of data.

A comprehensive and fully integrated system of data collection will reduce duplication of effort, enable improved benchmarking between sites, improve monitoring of stroke care, enable more specific identification of evidence gaps and drive quality improvement efforts within the health care system.

This component of the program will be integral to enable the health system to identify gaps and solutions via established, robust and collaborative methodology demonstrated to improve stroke care and patient outcomes.

Health professional education and ongoing quality improvement - StrokeLink

Funding support should be provided for a national rollout of StrokeLink, a comprehensive, multifaceted quality improvement program designed to link clinical audit data with best practice care outlined in the guidelines.

In Queensland, where the program is funded, StrokeLink offers a range of interventions including outreach visits by trained staff using interactive educational formats and local consensus processes, development of educational resources, regional planning and other collaborative activities.

A key component of the program is the identification of local barriers to implementation and the development of an agreed action plan to overcome these barriers using a local consensus approach.

A rapid quality improvement framework, plan-do-study-act (PDSA), then enables the agreed strategies outlined in the action plan to be tested. Ongoing support is also provided in the form of phone calls, emails, follow-up visits and linkage to other hospitals with clinicians facing similar issues.

Implementation of the above program will improve access to evidence based care that not only improves outcomes for stroke patients but also is highly cost effective. Improving access to stroke units and thrombolysis to levels similar to international benchmarks has the potential to save more than 9000 DALY's at a cost of under \$400 per DALY.⁵¹

4. Providing care and support that stroke survivors need to adjust to life after stroke

\$21m over three years

What is the problem?

Currently, an estimated 420,000 people are living after stroke in Australia.⁵² Stroke is a leading cause of death in Australia and a leading cause of disability amongst adults. The consequences of stroke can include paralysis, inability to speak, difficulty with memory and thinking or problems completing everyday activities such as dressing and eating. Between 20 and 30% of stroke survivors go on to develop vascular dementia suggesting that the increase in strokes over the next decade will add between 100,000 and 150,000 new cases of vascular dementia to the Australian community.⁵³

Survivors of stroke report difficulties that affect many facets of their lives. These range from physical to emotional problems and impact their ability to work and participate in social and family activities. The impact of a stroke is profound:

- Stroke survivors are more likely to have profound limitations relating to self-care, movement and communication than other people with disability.⁵⁴
- Health related quality of life (HRQoL) for the majority of stroke survivors up to two years after their stroke has been rated as very poor.⁵⁵
- Depression is seen in approximately one-third of survivors.⁵⁶

Most stroke survivors (74%) return home to the community and require ongoing care and support.⁵⁷ The burden of care most often falls to family members or friends with 57% of survivors receiving assistance from a family member (most often their spouse). Carers report the burden of care has a significant impact on all areas of their lives.⁵⁸

The recently released Call to Action developed by survivors and their families reflects the needs survivors and carers have in the community. Many of the areas of need reflected the significant adjustment a previously independent individual has to make when faced with sudden onset of disability and adjustment to the knowledge they have suffered a life-changing and chronic condition with an acute onset. Survivors describe the enormous emotional consequences of stroke and report there is little to assist

them in living with disability or adjusting to life after stroke when they go home.

Despite the fact evidence exists for effective models of care to improve life after stroke, and stroke survivors and carers describe these services as being important to their recovery, many stroke consumers report that access to services in the community to support their ongoing recovery is problematic and in fact the current situation is untenable.

In Australia:

- There is no comprehensive program to ensure survivors are systematically followed up by Stroke Liaison Workers or a similarly structured model of care.
- Only 50% of carers receive training prior to their partner coming home with care needs.⁵⁹
- Only 30% of survivors were satisfied with the information they received prior to leaving hospital and many report they are unable to access this easily in the community. They also report that information needs change over time so flexible and self-directed models of information provision are required. These also need to accommodate the needs of those who may have language or cognitive problems post stroke.⁶⁰
- Peer support programs are fragmented and difficult to access and only 59% of hospitals admitting stroke patients routinely inform survivors and carers of local peer support groups. In addition there are no mechanisms to facilitate transition to the groups.⁶¹

This situation is made more complex as interventions in the community must be responsive to changes over time and follow up may be required at different time points. This results in a high degree of unmet need which is detrimental to recovery, increasing dependence on others and impacting on quality of life.

What should be done?

There must be a coordinated approach to supporting stroke survivors in the community. An approach that is caring and focused on the individual and their carer, with recognition of the significant impact stroke is likely to have had upon both their lives.

Recognition of the long term needs of survivors in the community has prompted much research to identify models of care that can assist in recovery and support survivors and their carers in the adjustments to life after stroke.

Many effective models of care have been described and include:

- A Cochrane review of the Stroke Liaison Worker model which found follow up by a stroke liaison worker for survivors with mild to moderate disability resulted in a significant reduction in death and dependence. For every 100 survivors with mild to moderate disability who were seen by a stroke liaison worker, 11 fewer patients were dead or dependent.⁶²
- The provision of information and education to stroke survivors and carers is critically important. A range of randomised control trials have found that a variety of methods can be used to significantly improve knowledge and that active interventions that use methods which work with the stroke survivors to assimilate information and plan activities, has benefits in relation to anxiety and depression. In addition, education and information in the form of decision support aids provides patients with greater satisfaction with the decision making process, more realistic expectations and an ability to be more decisive about treatment options.⁶³
- Interventions to support informal carers including carer training, problem-solving, psycho-educational and social support interventions and a combination of education and counselling have been found to be beneficial.⁶⁴ Carer training provided during an inpatient stay has also been found to reduce total costs (UK study demonstrating mean savings of £4043), primarily reflecting savings due to earlier discharge from inpatient care, while also improving health outcomes.

Different modes of delivering support to carers, for example, using the telephone^{65,66} or the internet^{67,68} have been used and have potential benefits in reducing stress. Such interventions may be particularly useful for carers in more rural and remote parts of Australia.

- Self-management is identified as a key strategy to drive recovery by survivors and there are many models by which stroke survivors may be encouraged to manage their own recovery. The most thoroughly tested model is a generic six-week self-management program in which stroke survivors (without cognitive impairment) were provided with education about communicating with health professionals, managing change and setting and achieving goals.^{69,70,71} There are known to be small to moderate positive changes in health outcomes for people participating in generic self-management education programs,⁷² however, such programs are inaccessible by many stroke survivors because of cognitive or language impairment or severe disability. Stroke specific self-management programs have shown small effects in improving health related quality of life or maintained levels of function relating to family roles, activities of daily living, self-care and work productivity while levels in a control group declined. These programs also enable greater completion rates for survivors than generic models.⁷³

The National Stroke Foundation proposes a range of programs which will respond to stroke survivor and carer needs, improving their quality of life. These include:

- Comprehensive and coordinated follow up for all survivors that link them into existing systems and programs.
- Comprehensive and accessible self-management programs suitable for people with significant disability, as well as language and cognitive impairment.
- Carer training and information programs provided in hospital and extended into the community for carers of people with stroke.
- Comprehensive and accessible information about stroke, stroke recovery and changes over time.
- Coordinated and accessible peer support programs in the community.

Policy proposal	Action	Budget impact
Comprehensive coordinated follow up of stroke survivors and carers.	StrokeConnect.	\$10.5m over three years.
Self-management program.	Self-management program.	\$3m over three years.
Carer training.	Carer training.	\$3m over three years.
Education.	Information and education.	\$4.5m over three years.

Policy proposal detail

StrokeConnect: Comprehensive and coordinated follow up for all survivors and their carers.

It is proposed that the Australian Government provide \$10.5m over three years to support a national rollout of StrokeConnect. Funding of this program will ensure all Australian stroke survivors are contacted individually at specific time periods following their stroke for needs assessment and program and service referral.

The National Stroke Foundation has been piloting and developing the StrokeConnect model of care in response to survivor needs since 2008. StrokeConnect acknowledges that survivor needs are difficult to accurately predict on discharge and generally change over time, and that survivors frequently report that they are unable to navigate help in the community to support them with life after stroke and have to fight to find out what services may be available to them. Many of the services they value do not sit within one health system area (eg. primary or aged care) and some services are provided by social systems rather than the health system.

StrokeConnect comprises the:

- Establishment of a blanket, central referral process for every stroke survivor discharged home.
- Provision of phone follow-up (3x phone calls at 6, 12 and 20 weeks) to determine ongoing needs in the community (when they are most apparent).
- A broad assessment will be undertaken during each phone call. Both survivor and carer needs will be assessed in order to ensure the needs of both individuals are attended to. The assessment will focus on:
 - How the survivor and carer are managing since discharge;
 - What information gaps exist; and
 - What support/service gaps exist.
- Navigation (linking) of stroke survivors to services survivors report they are currently unable to access.

This model of follow up has been piloted in WA and Tasmania and demonstrates that:

- StrokeConnect is a program that is complementary to the care provided.
- Survivors are receptive to the program with all consenting to their details being shared with the National Stroke Foundation for the purpose of follow-up.

- StrokeConnect successfully meets an identified gap in information provision and provides support and access to peer programs.
- With assistance, stroke survivors and carers can be successfully linked with appropriate services via this telephone based model. Approximately 60% of consumers called had their needs met via the 2 standard telephone consultations.
- A significant number of survivors and carers have needs which have been unmet by the health and community sector. 40% of referrals required more support including a more detailed assessment and referral to services. This was consistent across calls made at 6 and 12 weeks.
- More consumers required intensive follow up at 12 weeks than at 6 weeks, demonstrating the need for assessment and support and different time points.

The outcomes of StrokeConnect, already evidenced through the conduct of pilot programs, are significant to stroke survivors and carers as well as the broader healthcare community, including:

- Improved coordination of care.
- Increased participation in programs that are proven to reduce the impact of stroke.
- Improved health related quality of life, mood and participation in community activities.

Self-management

It is proposed the Australian Government invest \$3m over three years in development and national rollout of stroke specific self-management programs for stroke survivors.

Self-management programs are recognised as an effective strategy for managing chronic conditions.⁷⁴ The challenge for the stroke community has been that most generic self-management programs are not suitable for people with severe physical disability, language difficulties and cognitive impairments meaning a large proportion of the stroke survivor population are unsuitable for these programs.

The National Stroke Foundation has developed and tested an eight-week stroke specific self-management program (SSMP). A single blind, multi-centred, Phase II Randomised Control Trial (RCT) found the program showed improvements in depression and social engagement/isolation domains and importantly that stroke survivors were four times more likely to complete the stroke specific program when compared to the Stanford program, a generic chronic disease self-management program.

Concurrent to this research activity the National Stroke Foundation has been exploring models of service delivery to identify the most successful and sustainable means of ensuring equity and increasing access to the program. A pilot which aimed to translate, test and evaluate a locally coordinated, locally delivered capacity building model of self-management support to enable local stroke services to deliver the stroke self-management program to the stroke population was undertaken in Queensland.

Working with 7 sites across metro and regional Queensland, health professionals and peer educators were trained and supported to deliver the program in hospital and community settings. The program was extremely well received by all health professionals and peer educators involved and importantly, delivered results comparable to the Phase II RCT – demonstrating that all stroke survivors (including those with cognitive and language impairment) were able to participate in and complete the program and had improved on the depression and social engagement/isolation domains.

Carer training

It is proposed the Australian Government provide \$3m over three years for a national carers training package to ensure carers of stroke survivors receive adequate information and support on how to meet care needs prior to going home from hospital.

Carers often report feeling inadequately trained, poorly informed and dissatisfied with the extent of support available after discharge. Evidence suggests that carers benefit from training in a range of activities related to care prior to discharge. The *Clinical Guidelines for Stroke Management 2010* recommend that carers and family members receive relevant training prior to the stroke survivor's discharge.

The National Stroke Foundation proposes the implementation of a national carers training program that supports care for people with disability after stroke, delivered in partnership with health care providers and carers organisations. This would be provided prior to leaving hospital and supported through the StrokeConnect program delivery in the community with additional support, if required, provided through community based care coordination arrangements.

Information and education

The Australian Government should contribute \$4.5m over three years to support development of a package of information and education material for stroke survivors and to assist with dissemination of the material to target audiences.

It is well established that information and education for people who have had a stroke are critical elements of support in their life post stroke. We also know information should be offered regularly over various time frames as information needs change over time.

Despite this, stroke consumers consistently talk about the lack of information provided to them and the difficulty they have in accessing relevant, current information.

Additionally, consumers speak of the lack of tools to support them in driving their own recovery. They ask for tools to assist them in setting goals, tools which will allow them to continue their own rehabilitation when the system can no longer support them, information which will more easily allow them to access services and support.

The National Stroke Foundation proposes the development and implementation of a broad ranging information program which includes the provision of hard copy and digital information, is available in a range of languages and takes account of language and cognitive impairment.

It is envisaged that this information program would contain:

- Static information on a range of topics including information about stroke, stroke prevention, the effects of stroke and other topics to support consumers in their information needs.
- Interactive tools which would support self-management approaches. These tools would support consumers to be more engaged with their care and recovery and support them to continue their rehabilitation through the provision of interactive, self directed rehabilitation tools.
- Education and information from survivors and experts that enables survivors and carers to adopt new approaches to everyday activities made more difficult by disabilities after stroke.
- A service to provide coordinated and timely support to consumers to seek out appropriate support and assistance in the community.

5. Research to develop the best ways to aid rehabilitation efforts and ensure adequate emotional and psychological support

\$33m over three years

What is the problem?

Of the 420,000 people living in Australia after a stroke, two-thirds have a disability that impedes their ability to carry out activities of daily living unassisted.⁷⁵

Rehabilitation is provided to many people after stroke with about half of those admitted to acute hospitals accessing some form of ongoing rehabilitation.⁷⁶ The time course of recovery varies and people affected by stroke may continue to improve for many months or even years following their stroke. Formal rehabilitation often needs to continue after discharge from hospital and there is some evidence to demonstrate provision of rehabilitation therapy services in the community (home or centre-based) within the first year after stroke improves outcomes^{77,78} and home-based rehabilitation may be cheaper than centre-based therapy.⁷⁹ Furthermore, those who participate in home based rehabilitation have a lower risk of readmission and lower carer strain than those who receive centre-based rehabilitation.⁸⁰ Whilst the major part of physical recovery following stroke usually occurs within the first six months, further input can enhance recovery and/or prevent the decline that frequently occurs after stroke and can lead to hospital readmission. This may be delivered either at home⁸¹ or in residential aged care facilities.⁸²

Despite strong evidence for the benefits associated with rehabilitation and the knowledge that improvements can be seen long term after stroke, many survivors are not able to access rehabilitation or are discharged long before they have achieved their rehabilitation goals. Home-based rehabilitation is not a common model of care in Australia and access to such services is variable.

Data shows there are significant wait times for access to rehabilitation once you have been discharged from hospital. Outpatients fare worst with a mean wait time of more than 50 days; day program participants wait for nearly 30 days on average and those receiving rehabilitation in the home face a wait of more than 20 days.⁸⁰

The data also shows outpatients have on average the longest access to programs at around 170 days with home based therapy around 85 days and day patients receiving an average of around 75 days.⁸³

In addition to the significant physical disability commonly experienced by stroke survivors, mood is also frequently affected following a stroke. Depression is the most common mood disturbance with approximately one-third of patients experiencing depression after stroke.⁸⁵ Anxiety, emotional ability and personality and behavioural changes (e.g. irritability, aggression, apathy, emotional ability) are also common after stroke and can lead to significant impediments to community participation and reintegration.^{86,87,88,89} Such changes also pose difficulties for family, friends and carers, significantly contributing to carer burden and stress.^{90,91} There is limited specific research on assessment and rehabilitation of behaviour management.

While some people with mood disturbances may recover spontaneously over a few months, others may have problems that persist despite active interventions.⁹²

Studies that have compared pharmacological agents or psychological therapy versus placebo or standard care for the prevention of depression following stroke show small positive benefits of psychological strategies and supports the use of more structured approaches to the delivery of education and advice targeting emotional recovery and adjustment to the effects of stroke.⁹³ Survivors report emotional and psychological support, with or without a formal diagnosis of depression or mood disorder, is critical for their ongoing recovery and adjustment to life after stroke.

Despite the prevalence of mood disorders after stroke, and survivors belief support should be provided with or without a formal diagnosis of depression, there is limited understanding of appropriate forms of emotional and psychological support for stroke survivors. Similarly, there is limited understanding in the community of how survivors and their families may best access and use existing mental health services and community programs (such as peer support).

Despite the significant burden of post stroke physical and emotional disability on people affected by stroke, their families and the community, and the large knowledge gaps on how best to address this burden, stroke rehabilitation research is chronically underfunded. Since 2003, only 20 NHMRC project grants have been awarded in this area with a total outlay of \$11 million dollars – just over \$1 million a year. A further \$5.5 million has been awarded for fellowships, scholarships or to rehabilitation centres for research excellence (Aphasia) since that time.⁹⁴

Chronic underfunding is an issue for stroke research generally and this has hampered the ability for the small stroke research community to build capacity in its ranks. There is a subsequent shortage of research leaders who are required to compete for large competitive research grants and the lack of support for research collaboration in stroke ensures the little research that does take place is often done in isolation resulting in inefficiency and lack of impact.

The end result is low understanding of a disease whose burden outweighs nearly all others in Australia. It is an understanding that will struggle to be built upon in the current research environment despite the best efforts of some outstanding, albeit under-represented and under-resourced research minds.

What should be done?

The Australian Government should invest in the establishment of a formal stroke research network and provide three years of dedicated stroke research funding focused on key areas of need.

Health professionals, consumers and researchers recognise the need for rehabilitation programs to be further developed to enable survivors to maximise gains longer term, whilst freeing the health system up to provide rehabilitation intensively in the early stage of recovery. Current models are inflexible, time-limited and access is dependent on the geographical location of the consumer.

Significant investment in research funding is required to support research that develops and tests more flexible, patient centred models of care that support consumers throughout their often long term recovery. These models of care should consider how best to engage the survivors and carers in self directed activity, with or without support from the health system and should consider use of technological advances including Smartphone/ tablet and telehealth technology that supports models of remote monitoring and coaching if required.

Research should address:

- Alternative ways to provide emotional and psychological support to survivors/carers.

- Better ways for existing mental health services to meet the needs of people with stroke.
- Gaps in stroke rehabilitation services and how these can be addressed, including the issue of how long term recovery is supported.
- The best models of stroke rehabilitation that would include self directed or supported (rather than therapist-provided only) models of care.

This research should be informed by consumers, and commercial opportunities relating to techniques under development should also be considered – for example innovative technology-based rehabilitation models.

Opportunities for innovation provided by the National Broadband Network (NBN) should also be explored.

A formal stroke research network should be established to underpin and provide a coordination framework for efforts to better understand key stroke issues.

In Australia, research networks have been developed in other areas such as intensive care, kidney and sleep research and are currently being developed for paediatrics. These established and planned networks all address common problems with clinical research and address remarkably similar issues.

Internationally, a number of countries have established such networks to improve the efficiency and effectiveness of national stroke research programs. They complement competitive research funding programs by facilitating communication between researchers and clinicians, build infrastructure and infrastructure sharing, building career pathways and enhancing the care and management of patients and carers.

In Britain, the National Institute for Health Research (NIHR) Stroke Research Network aims to facilitate stroke research by bringing about focused, effective investment to enhance NHS research infrastructure for stroke and to increase collaborative working between academics, stroke clinicians, stroke service users and research funders.

The Network has seen considerable success with its study portfolio increasing from 26 open studies in April 2006 to 91 in January 2011, with another 16 in set-up phase. The number of hospital stroke services in England recruiting into SRN studies increased from 57 in the first quarter of 2006 to 189 in the fourth quarter of 2009.

A stroke research network in Australia would provide impetus for capacity building, collaboration and cooperation that will result in more efficient and higher impact research to build a greater understanding of stroke and lead to development of new and refined treatment and care options that will improve outcomes for stroke patients.

Policy proposal	Action	Budget impact
Provide framework for coordinated, cooperative stroke research focused on key identified stroke issues.	Fund the establishment of an Australian Stroke Research Network.	\$3m over three years.
Support dedicated research into key identified stroke issues.	Establish a dedicated stroke research fund with remit to focus on an agreed set of stroke priorities and a competitive framework for funding distribution.	\$30m over three years.

Policy proposal detail

The Australian Government should provide \$3m to establish an Australian Stroke Research Network to provide a platform for an expanded, cooperative, efficient and high impact national research program in stroke.

The Network will facilitate collaboration between stroke focused researchers across Australia and build stroke research workforce capacity ensuring the best minds in the limited field of stroke research are joined up and supported to tackle the key stroke research issues outlined above.

This investment would provide the ability for communication and networking between stroke researchers, clinicians and stroke patients on important

stroke research questions – a process which has shown to improve the development of research questions and increase the success of translation efforts.

The Australian Stroke Research Network should be supported with the injection of \$30m of dedicated competitive research funding over three years to seed fund a set of key research projects. The Terms of Reference for the dedicated stroke research fund should be developed in consultation with the broader stroke community including representatives from clinical networks, research groups, stroke survivors and carers and peak bodies such as Stroke Society Australasia and the National Stroke Foundation.

References

1. Deloitte Access Economics - *The economic impact of stroke in Australia* 2013
2. Australian Institute of Health and Welfare, Australia's health 2010. 2010, AIHW.
3. Australian Institute of Health and Welfare, Australia's health 2010. 2010, AIHW.
4. Australian Institute of Health and Welfare, Prevention of cardiovascular disease, diabetes and chronic kidney disease: targeting risk factors. Cat. no. PHE 118. 2009, AIHW: Canberra
5. Australian Institute of Health and Welfare, Australia's health 2010. 2010, AIHW.
6. Australian Institute of Health and Welfare, Prevention of cardiovascular disease, diabetes and chronic kidney disease: targeting risk factors. Cat. no. PHE 118. 2009, AIHW: Canberra.
7. Australian Health Survey: First Results, 2011-12 , Australian Bureau of Statistics, Canberra, 2012.
8. Australian Health Survey: First Results, 2011-12 , Australian Bureau of Statistics, Canberra, 2012.
9. AIHW 2009 – data summarised in National Vascular Disease Prevention Alliance Position Paper, May 2011, Risk awareness raising, assessment and management for the prevention of vascular and related diseases.
10. Australian Institute of Health and Welfare. 2009. Prevention of cardiovascular disease, diabetes and chronic kidney disease: targeting risk factors. Cat. No. PHE 118. Canberra: AIHW.
11. Stacey D, Bennett CL, Barry MJ, Col NF, Eden KB, Holmes-Rovner M, Llewellyn-Thomas H, Lyddiatt A, Légaré F, Thomson R. Decision aids for people facing health treatment or screening decisions. Cochrane Database of Systematic Reviews 2011, Issue 10. Art. No.: CD001431. DOI: 10.1002/14651858.CD001431.pub3.
12. Thistlethwaite, Jill, Evans, Rebecca, Nan Tie, Rodney, and Heal, Clare (2006) Shared decision making and decision aids. Australian Family Physician, 35 (7). pp. 537-540.
13. Man-Son-Hing M, Laupacis A, O'Connor AM, et al. A patient decision aid regarding antithrombotic therapy for stroke prevention in atrial fibrillation: a randomised controlled trial. JAMA 1999;282:737-43.
14. Shared decision making and decision aids, A literature review, Jill Thistlethwaite BSc, MBBS, MMed, FRCP, FRACGP, DRCOG.
15. Edwards A, Elwyn G. The potential benefits of decision aids in clinical medicine. JAMA 1999;282:779-80.
16. National Stroke Foundation Business Case for 'Know your numbers' December 2010.
17. National Stroke Foundation Business Case for 'Know your numbers' December 2010.
18. NVDPA Position Paper, Risk awareness raising, assessment and management for the prevention of vascular and related diseases, May 2011.
19. Webster P, Radberg J, Lundgren B, Peltonen M. (1999) Factors associated with delayed admissions to hospital and in-hospital delays in acute stroke and TIA. Stroke; 30: 40-48.
20. National Stroke Foundation. National Stroke Awareness Survey. Unpublished data. 2011.
21. Easton JD, Saver JL, Albers GW, Alberts MJ, Chaturvedi S, Feldmann E, Hatsukami TS, Higashida RT, Claiborne Johnston S, Kidwell CS, Lutsep HL, Miller E, Sacco RL. Definition and Evaluation of Transient Ischemic Attack: A Scientific Statement for Healthcare Professionals From the American Heart Association/American Stroke Association Stroke Council; Council on Cardiovascular Surgery and Anesthesia; Council on Cardiovascular Radiology and Intervention; Council on Cardiovascular Nursing; and the Interdisciplinary Council on Peripheral Vascular Disease. Stroke 2009;40:2276-2293.
22. Giles MF, Rothwell PM. Risk of early stroke after transient ischaemic attack: a systematic review and meta-analysis. Lancet Neurol, 2007; 6: 1063-72.
23. Ferro et al, 1994; Wester et al, 1999.
24. National Stroke Foundation (2011) National Stroke Audit Acute Services Organisational Survey Report 2011.
25. National Stroke Foundation (2011) National Stroke Audit Acute Services Organisational Survey Report 2011.
26. Recombinant tissue plasminogen activator for acute ischaemic stroke: an updated systematic review and meta-analysis. Wardlaw JM, Murray V, Berge E, del Zoppo, G, Sandercock P, Lindley RJ, Cohen G. Lancet 2012; 379: 2364-72.
27. Silvestrelli, G., et al., Early admission to stroke unit influences clinical outcome. European Journal of Neurology, 2006, 13: p. 250-255.
28. Cadilhac, unpublished data 2010.
29. National Stroke Foundation. Clinical guidelines for stroke management 2010. Melbourne Australia.
30. Stroke Unit Trialists' Collaboration. Organised inpatient (stroke unit) care for stroke. Cochrane Database of Syst Rev 2007.
31. Recombinant tissue plasminogen activator for acute ischaemic stroke: an updated systematic review and meta-analysis Joanna M Wardlaw, Veronica Murray, Eivind Berge, Gregory del Zoppo, Peter Sandercock, Richard L Lindley, Geoff Cohen, The Lancet 23 June 2012 (Volume 379 Issue 9834 Pages 2364-2372 DOI: 10.1016/S0140-6736(12)60738-7).
32. Antithrombotic Trialists Collaboration. Collaborative meta-analysis of randomised trials of antiplatelet therapy for prevention of death, myocardial infarction, and stroke in high risk patients. BMJ. 2002;324:71-86.
33. Sandercock PAG, Counsell C, Gubitz GJ, Tseng MC. Antiplatelet therapy for acute ischaemic stroke. Cochrane Database of Systematic Reviews. 2008;Issue 3:CD000029.
34. Lakhan SE, Sapko MT. Blood pressure-lowering treatment for preventing stroke recurrence: a systematic review and meta-analysis. International archives of medicine. 2009;2(1):30.
35. Lakhan SE, Sapko MT. Blood pressure-lowering treatment for preventing stroke recurrence: a systematic review and meta-analysis. International archives of medicine. 2009;2(1):30.
36. Outpatient Service Trialists. Therapy-based rehabilitation services for stroke patients at home. Cochrane Database of Syst Rev. 2003;Issue 1. CD002925.
37. National Stroke Foundation. National Stroke Audit Acute Services Organisational Survey Report 2009. Melbourne Australia.
38. National Stroke Foundation. National Stroke Audit Acute Services Clinical Audit Report 2009. Melbourne Australia.
39. National Stroke Foundation. National Stroke Audit Rehabilitation Services 2010. Melbourne Australia.
40. National Stroke Foundation. National Stroke Audit Acute Services Organisational Survey Report 2011. Melbourne Australia.
41. National Stroke Foundation. National Stroke Audit Acute Services Clinical Audit Report 2011. Melbourne, Australia (unpublished report).
42. National Stroke Foundation (2011) National Stroke Audit Acute Services Organisational Survey Report 2011.
43. National Stroke Foundation (2011) National Stroke Audit Acute Services Organisational Survey Report 2011.
44. National Stroke Foundation (2011) National Stroke Audit Acute Services Organisational Survey Report 2011.
45. Cadilhac DA, Carter RC, Thrift AG, Dewey HM. Why invest in a national public health program for stroke? An example using Australian data to estimate the potential benefits and cost implications. Health Policy. 2007 Oct;83(2-3):287-94.
46. UK Department of Health, National Stroke Strategy, 2007.
47. Silvestrelli, G., et al., Early admission to stroke unit influences clinical outcome. European Journal of Neurology, 2006, 13: p. 250-255.
48. National Stroke Foundation (2011) National Stroke Audit Acute Services Organisational Survey Report 2011.
49. Australian Commission on Safety and Quality in Health Care. Operating Principle and Technical Standards for Australian Clinical Quality Registries ACSQ 2008.

50. Australian Commission on Safety and Quality in Health Care. Operating Principle and Technical Standards for Australian Clinical Quality Registries ACSQ 2008.
51. Cadilhac DA, Carter RC, Thrift AG, Dewey HM. Why invest in a national public health program for stroke? An example using Australian data to estimate the potential benefits and cost implications. *Health Policy*. 2007 Oct;83(2-3):287-94.
52. Deloitte Access Economics - *The economic impact of stroke in Australia* 2013
53. Mackowiak-Cordoliani, M.A., et al., Poststroke dementia in the elderly. *Drugs Aging*, 2005. 22(6): p. 483-93.
54. Australian Institute of Health and Welfare, Australia's health 2010. 2010, AIHW.
55. Sturm, J.W., et al., Determinants of handicap after stroke: the North East Melbourne Stroke Incidence Study (NEMESIS). *Stroke*, 2004. 35(3): p. 715-20.
56. Hackett, M.L., et al., Frequency of depression after stroke: a systematic review of observational studies. *Stroke*, 2005. 36(6): p. 1330-40.
57. National Stroke Foundation, National Stroke Audit Acute Services Clinical Audit Report 2009. 2009: Melbourne, Australia.
58. National Stroke Foundation, Walk in our shoes. 2008, NSF: Melbourne.
59. National Stroke Foundation, National Stroke Audit Acute Services Clinical Audit Report 2009. 2009: Melbourne, Australia.
60. National Stroke Foundation, Walk in our shoes. 2008, NSF: Melbourne.
61. National Stroke Foundation. National Stroke Audit – Acute Services Organisational Survey Report 2011. Melbourne Australia.
62. Legg, L., et al., Occupational therapy for patients with problems in personal activities of daily living after stroke: systematic review of randomised trials. *Bmj*, 2007. 335(7626): p. 922.
63. Thistlethwaite, Jill, Evans, Rebecca, Nan Tie, Rodney, and Heal, Clare (2006) Shared decision making and decision aids. *Australian Family Physician*, 35 (7). pp. 537-540.
64. Lee J, Soeken K, Picot SJ, Lee J, Soeken K, Picot SJ. A meta-analysis of interventions for informal stroke caregivers. *West J Nurs Res*. 2007;29(3):344-56.
65. HartkeRJ, King RB. Telephone group intervention for older stroke caregivers. *Top Stroke Rehabil*. 2003;9(4):65-81.
66. Grant JS. Social problem-solving partnerships with family caregivers. *Rehabil Nur*. 1999;24(6):254-60.
67. PierceLL, Steiner V, Govoni AL, Hicks B, Cervantez Thompson TL, Friedemann ML. Internet-based support for rural caregivers of persons with stroke shows promise. *Rehabil Nurs*. 2004;29(3):95-9,103.
68. PierceLL, Steiner V, Khuder SA, Govoni AL, Horn LJ. The effect of web based intervention on carers' wellbeing and survivors' use of healthcare services *Disabil.Rehabil*.2009;31(20):1676-84.
69. Fu D, Fu H, McGowan P, Shen YE, Zhu L, Yang H, et al. Impelmentation and qantative evaluation of chronis disease self management program in Shanghai, China; randomized control trail. *Bull Worls Health Organ*. 2003;81(3):174-82.
70. Lorig KR, Ritter P, Stewart AL, Sobel DS, Brown BW, Jr., Bandura A et al. Chronic disease self management program: 2 year health status and health care utilization outcomes. *Medical Care*. 2001;39(11):1217-23.
71. Lorig KR, Sobel DS, Stewart AL, Brown BW, Jr., Bandura A, Ritter P et al. Evidence suggesting that a chronic disease self management program can improve health status while reducing hospitalization: a randomized control trial. *Medical Care*. 1999;37(1):5-14.
72. Warsi A, Wang PS, Lavalley MP, Avorn J, Solomon DH. Self management education programs in chronic disease: a systematic review and methodological critique of the literature. *Arch Intern Med*. 2004;164(15): 1641-9.
73. Dominique A. Cadilhac, Sally Hoffmann, Monique Kilkenny, Richard Lindley, Erin Lalor, Richard H. Osborne and Malcolm Batterbsy. A Phase II Multicentered, Single-Blind, Randomized, Controlled Trial of the Stroke Self-Management Program. *Stroke* 2011, 42:1673-1679.
74. National Health Priority Action Council (2006) National Chronic Disease Strategy Australian Government Department of Health and Ageing, Canberra.
75. Deloitte Access Economics - *The economic impact of stroke in Australia* 2013
76. National Stroke Foundation. National Stroke Audit Acute Services Clinical Audit Report 2011. Melbourne, Australia (unpublished report).
77. Outpatient Service Trialists. Therapy-based rehabilitation services for stroke patients at home. *Cochrane Database Syst Rev*. 2002, Issue 2. CD002925.
78. Hillier S, Gakeemah I. Rehabilitation for community-dwelling people with stroke: home or centre based? A systematic review. *Int J Stroke*. 2010;5(3):Published online May 5.
79. Britton M, Andersson A. Home rehabilitation after stroke: reviewing the scientific evidence on effects and costs. *Int J Technol Assess Health Care*. 2000;16(3):842-8.
80. Crotty M, Giles LC, Halbert J, Harding J, Miller M. Home versus day rehabilitation: a randomised controlled trial. *Age Ageing*. 2008;37(6):628-33.
81. Outpatient Service Trialists. Therapy-based rehabilitation services for stroke patients at home. *Cochrane Database Syst Rev*. 2002, Issue 2. CD002925.
82. Sackley C, Wade DT, Mant D, Atkinson JC, Yudkin P, Cardoso K, et al. Cluster randomized pilot controlled trial of an occupational therapy intervention for residents with stroke in UK care homes. *Stroke*. 2006;37(9):2336-41.
83. The Out-and-about trial: Feedback from audits of medical records for people with stroke treated by 23 non- inpatient services in NSW. Unpublished data. Dr Annie McCluskey, The University of Sydney, 23 November 2012.
84. The Out-and-about trial: Feedback from audits of medical records for people with stroke treated by 23 non- inpatient services in NSW. Unpublished data. Dr Annie McCluskey, The University of Sydney, 23 November 2012.
85. Hackett ML, Yapa C, Parag V, Anderson CS. Frequency of depression after stroke: A systematic review of observational studies. *Stroke*. 2005;36(6):1330-40.
86. Kelly G, Brown S, Todd J, Kremer P. Challenging behaviour profiles of people with acquired brain injury living in community settings. *Brain Injury*. 2008;22(6):457-70.
87. Murray J, Young J, Forster A. Review of longer-term problems after a disabling stroke. *Reviews in Clinical Gerontology*. 2007;17:277-92.
88. Hochstenbach J, Prigatano G, Mulder T. Patients' and realtives' reports of disturbances nine months after stroke: subjective changes in physical functioning, cognition, emotion and behaviour. *Arch Phys Med Rehabil*. 2005;86:87-93.
89. Stone J, Townend E, Kwan J, Dennis MS, Sharpe M. Personality change after stroke: some preliminary observations. *J Neurol Neurosurg Psychiatry*. 2004;75:1708-13.
90. Murray J, Young J, Forster A. Review of longer-term problems after a disabling stroke. *Reviews in Clinical Gerontology*. 2007;17:277-92.
91. Stone J, Townend E, Kwan J, Dennis MS, Sharpe M. Personality change after stroke: some preliminary observations. *J Neurol Neurosurg Psychiatry*. 2004;75:1708-13.
92. Hackett ML, Yapa C, Parag V, Anderson CS. Frequency of depression after stroke: A systematic review of observational studies. *Stroke*. 2005;36(6):1330-40.
93. Hackett ML, Anderson CS, House A, Halteh C. Interventions for preventing depression after stroke. *Cochrane Database Syst Rev*. 2008, Issue 3. CD003689.
94. NHMRC research funding audit, 7 November 2012.



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