Federal Pre-Budget Submission 2021-22

Action to tackle stroke

- **In partnership with the Australian Government, Stroke Foundation will empower Australians to live healthier lives through effective prevention, treatment and management of heart disease and stroke. This is the goal of the National Strategic Action Plan for Heart Disease and Stroke, currently under consideration by Government.**
- **Stroke Foundation's 2021–2022 Federal Pre-Budget Submission sets out key actions to address The Action Plan's objectives and reach its goal. Actions will tackle two of this country's biggest killers, and will improve lives, which will benefit the community and economy, and contribute to health system sustainability.**
- **Acting to reduce uncontrolled hypertension (high blood pressure [BP]) in the community could mean thousands of Australians avoiding stroke. Providing greater access to emergency stroke treatments could mean increased stroke survival and more Australians living well after stroke. Together, this would equate to savings of $179.0 million over five years in economic costs, and $2.4 billion in reduced mortality and improved wellbeing annually.[1]**
- **We have an opportunity to act to change the course of this disease, and deliver a better health system now, and for generations for come. It's an investment we can, and must make.**

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The facts about stroke in Australia

- In 2020, more than 27,000 Australians experienced stroke for the first time, that is one stroke every 19 minutes, and there were almost 450,000 stroke survivors living in the community.[2]
- The economic cost of stroke in Australia exceeded $6.2 billion in 2020, with a further $26.0 billion in lost wellbeing - due to short and long-term disability, and premature death.[1]
- Stroke killed almost 8000 Australians in 2020 and left many with ongoing disability.[2]
- More than 80 percent of strokes can be prevented[3] and stroke can be treated.
- Australia's regional and rural communities are those most impacted by stroke. Australians living in these areas were 17 percent more likely to experience a stroke compared with their metropolitan counterparts.[2]
- Recognised disadvantage sees the burden of disease for stroke is 2.3 times as high among Aboriginal and Torres Strait Islander people compared with non-Indigenous Australians.[4]
- Increased risk associated with lifestyle factors links an overrepresentation of stroke in our regional, rural, and remote areas and in Indigenous Australians.[2]
- An increasingly sedentary lifestyle is seeing an increase in stroke incidence among Australians of working age.[2]
- In 2020, an estimated 29 strokes were experienced by Australians of working age each day.[2] In 2014, the percentage of first-ever strokes among people aged 54 years and under was 14 percent, in 2020 this increased to 24 percent.[2] This increase in stroke among working age Australians is consistent with international trends[5], and represents a significant impact on productivity, the economy and families.
- Without action, it is estimated by 2050 more than 50,000 new strokes will be experienced by Australians annually, and there will be more than 800,000 Australians living with the impact of this disease.[2]

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Stroke in the coronavirus (COVID-19) pandemic

Stroke Foundation recognises the COVID-19 pandemic was unprecedented, and applauds the Federal Government for its quick action to keep Australians safe. Survivors of stroke are among our community's most vulnerable to the disease.

As we transition from an emergency response to the pandemic to a management and recovery phase, there are lessons we can take from this country's successful approach, and apply to the health system moving forward. This includes the benefits a coordinated national action plan to prevent disease, the expansion of telehealth services, and furthering the case for rapid research translation into best clinical practice.

There are also ongoing challenges that will impact both the health of Australians, and the health system, due to indirect and direct consequences of the pandemic. This includes a possible increase in stroke incidence, due to delayed treatments and fear of exposure to the virus in hospitals during the early phases of the pandemic.

During the height of the pandemic, Australians were not visiting their general practitioner to have risk assessments to manage chronic conditions, calls to triple zero (000) decreased, meaning further delays in treatment, and our lifestyle was more sedentary. In addition, those who experienced a stroke during this period were not being connected to rehabilitation services or provided with the secondary prevention information they need to recover well. Continuity of care was a major challenge, and the impact of this is being felt as the country emerges from various restrictions and adapts to living in a COVID-19 world. There is also some evidence from the United States and Europe suggesting COVID-19 may lead to an increased stroke risk among younger people.[6]

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National Strategic Action Plan for Heart Disease & Stroke Priority 1: Prevention & Early Detection

Proposal: Stroke Pathways - Stroke prevention through a complete pathway of care involving patients and health professionals in general practice.

Actions:

1.1.3 Develop comprehensive screening via primary care for atrial fibrillation (AF).

1.1.4 Raise awareness for health checks and screening promotion activities at appropriate ages.

1.1.5 Improve management of people at high risk of, or living with, heart disease and stroke through primary care.

1.1.6 Provide health professionals with appropriate tools and resources to support screening and care.

Investment: $1 million over three years.

Impact: This project will provide evidence for a national roll out of the program, which if implemented, has the potential to deliver health economic savings of $400 million per annum from early detection and improved management of atrial fibrillation (AF), and $1.3 billion over five years from reducing uncontrolled high BP from 23 percent to 17 percent.[1]

Implementation

Implementation of a seamless workflow process within general practice to improve awareness and uptake of screening for both high BP and AF. Screening will be supported by an evidence-based management pathway, complemented by consumer education and monitoring of patient adherence to therapy.

Delivered in partnership by Stroke Foundation, the Department of General Practice, University of Melbourne and the Heart Rhythm and Stroke group, Heart Research Institute, this project is based on previous successful work.

It will target 30 general practices across New South Wales and Victoria.

Deliverables

- Suite of innovative eHealth tools that will be integrated with the patient electronic medical record, to support recall, screening, management, and adherence review.
- Structured training and case-based clinician education sessions to raise awareness of integrated health checks among health professionals.
- Consumer information and education to raise awareness of integrated health checks in the community.
- Recall messages for consumers to promote attendance for health checks and review medication adherence.

Evaluation

Evaluation will concentrate on the following elements:

- Adherence and fidelity with the protocol.
- Barriers, enablers and practicalities of delivering the intervention, determined by interviews with practice staff.
- Patient attitudes and experiences of the program, determined by interview.
- Proportion of eligible patients screened for AF and high BP.
- Proportion of patients appropriately treated according to guidelines.
- Rates of patient persistence to medications measured one year after completion of the project.

The opportunity

Recognition and management of high BP and AF is proven to reduce death and major disability caused by stroke.

An estimated 4.7 million Australians are living with high BP, with 387,000 Australians living with AF.[2]

Management of high BP in general practice remains suboptimal and is a causal factor in many strokes. Failed recognition of asymptomatic AF, and insufficient guideline-mandated anticoagulant therapy, or reduced therapy persistence, is a factor leading to

up to one third of all strokes caused by clots – the most common type of stroke. Both high BP and AF are amenable to interventions aimed at general practitioners, their patients, and the community, which could significantly reduce the high costs and burden of disability related to preventable strokes.

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Proposal: Right Monitor, Right Method, Right Result will empower Australians to identify and manage high blood pressure, avoiding stroke and heart disease.

Actions:

1.1.5 Improve management of people at high risk, or living with, heart disease and stroke through primary care.

1.1.6 Provide health professionals with the appropriate tools and resources to support screening and care.

Investment: $1 million over three years.

Impact: Move towards preventing an estimated 1,217 Australians from experiencing a stroke (2020).[1] Currently, the rate of uncontrolled high BP in Australia is 23 percent.[7] It is estimated uncontrolled high BP was attributed to be the cause of 5,536 strokes in 2020.[1] With action, a reduction in the rate of uncontrolled high BP to 17 percent could be achieved.[1]

Implementation

Right Monitor, Right Method, Right Result will encourage best-practice BP measurement through use of validated (tested) monitors, empowering Australians to identify and manage high BP, avoiding stroke and heart disease.

Stroke Foundation and Heart Foundation will partner with the University of Tasmania, High Blood Pressure Research Council of Australia (HBPRCA), Pharmaceutical Society of Australia (PSA) and NPS MedicineWise, to deliver this world-first national awareness and education program to improve BP measurement for consumers and pharmacists.

Deliverables

- Development of pharmacy evidence-based guidance on the use and supply of validated BP monitors.
- Education activities for pharmacists and consumers on the importance of only purchasing and using validated BP monitors.

- Information provision to pharmacists and consumers about which BP monitors available in Australia are validated, and encourage consumer purchasing of validated monitors.
- Education activities for pharmacists and consumers on the best-practice in-pharmacy and home BP measurement protocols.
- A high BP awareness campaign focusing on best-practice BP measurement, leveraging from existing annual campaigns of the project partners.

Evaluation

Evaluation will be focused on the following outcomes:

- Pre- and post-implementation home BP measurement awareness, knowledge and skills (pharmacists and consumers).
- Pre- and post-implementation level of awareness regarding the importance of using a validated BP monitor for accurate home BP measurement (pharmacists and consumers).
- Consumer feedback regarding educational resources and tools.
- Pharmacist feedback regarding educational resources and tools.
- Website and social media engagement and reach.
- Number of Australians with uncontrolled high BP post-implementation.

"The major concern with high blood pressure is many people don't realise they have it. It has no immediate symptoms, but over time, it damages blood vessels and increases the risk of stroke and heart disease."

Professor Bruce Campbell
Chair, Stroke Foundation Clinical Council

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The opportunity

High BP is the biggest risk factor for stroke and heart disease, and affects one in three Australian adults.[7] It is also the most modifiable risk factor. The first step in reducing the risks of high BP is accurate measurement.

Monitoring of BP at home is recommended in clinical guidelines for high BP management; however, currently, less than one quarter of BP monitors available for sale in Australian pharmacies have been appropriately validated for accuracy.[8] Millions of Australians who rely on these devices for home BP monitoring may be getting incorrect and harmful information. Negative outcomes result from inaccurate BP readings, including unnecessary medications, the stigma of having high BP, and missed opportunities to prevent CVD.

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Proposal: Living Well After Stroke.

Actions:

1.1.5 Improve management of people at high risk, or living with, heart disease and stroke through primary care.

1.1.6 Provide health professionals with the appropriate tools and resources to support screening and care.

Investment: $735,000 over three years.

Impact: Reduce the estimated 4,114 Australians who experienced a stroke in 2020 going on to experience another stroke (15 percent)[9], benefiting the community, health system and economy by:

- Closing treatment gaps: In 2019, 24 percent of stroke patients did not receive advice on risk factors during their admission, and 33 percent were not prescribed appropriate medication to manage high BP.[10]
- Increase prescribing of, and adherence to, medication, to decrease risk of stroke.
- Applying lessons from this program to people who have a transient ischaemic attack (TIA), and to other chronic diseases with modifiable risk factors.

Implementation

Living Well After Stroke will improve post-discharge support, by delivering education and support for behaviour change and better coordinated care, and will focus on survivors of stroke who have:

- Experienced a mild stroke, with no referral for ongoing rehabilitation.
- An identified need to change health behaviours to reduce their risk of future stroke.

The Program will target health behaviours including physical activity, healthy diet, safe consumption of alcohol and smoking cessation. This will be done through a person-centred approach that utilises the Health Action Process Approach.

Deliverables

- Individual and group assessments for participants.
- Group and telephone-based health coaching for participants.
- Participants, referred by acute and rehabilitation services, will receive seven sessions with an allied health professional, covering a range of topics including choosing health behaviours to focus on, development of SMART goals, individualised action plan, monitoring progress, and tackling setbacks.
- Education and interventions tailored to each individual, in line with their needs and preferences.
- Participants' GPs (with their consent) will be provided with information about the participant's goals and activities, supporting effective medical management of risk factors and improved continuity of care.
- Group sessions will allow people to connect with peers, to exchange advice and support.

Evaluation

Evaluation will focus on the impact of the program on health behaviours, stroke risk and coordination of care. To measure the impact of program activities, a number of evaluation methods will be used, including pre- and post-implementation surveys. Data on the following outcomes will be collected:

- Number of referrals into the program.
- Number of participants enrolled in the program.
- Action items identified and achieved.
- Service coordination.

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Lyn Larkins was 52 when she suffered a stroke. Before her stroke, Lyn had been neglecting her health for many years. Her cholesterol was high. She had out of control diabetes and was very overweight – a size 20. After the stroke she turned her health around. Changing the food she ate and educating herself about what was in the food was a big part of her recovery.

"I always thought the way I was before was the norm. Now that I eat well, exercise and feel wonderful, I think I should have made all of these changes years ago."

Lyn Larkins
Survivor of stroke

The opportunity

An estimated 27,428 Australians experienced stroke for the first time in 2020.[2] Fifteen percent of people will have another stroke in the five years after their first stroke.[9] At this time, a unique opportunity exists to support health behaviour change.

More than 80 percent of strokes can be prevented.[3] The Clinical Guidelines for Stroke Management state stroke patients should be assessed and informed of their risk factors for recurrent stroke, and educated about strategies to reduce their risk, yet in 2019, 24 percent of stroke patients did not receive advice on risk factors during their admission.[10]

For those with mild stroke, and no rehabilitation admission, short lengths of stay reduce opportunities for health behaviour education and intervention. Post discharge, there is no clear pathway for effective, evidence-based education and intervention to support health behaviour change. This underserviced group is at risk of falling through the gaps after a first stroke.

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National Strategic Action Plan for Heart Disease & Stroke Priority 2: Diagnosis and treatment

Proposal: An Australian Telestroke Network (ATN) will seamlessly connect emergency departments in selected regional hospitals to a roster of metropolitan-based neurologists, ensuring equity of access to stroke reperfusion therapies.

Actions:

2.1.1 Improve the delivery of emergency stroke treatment to regional and rural Australians.

Investment: Costings would be developed in consultation with Federal and State and Territory Health Departments.

Impact: Hundreds of lives saved, thousands of lives changed, and an estimated $1.2 billion in economic and wellbeing costs saved, by improving access and timelines to stroke treatment (5 years)[1]:

- Achieve a thrombolysis (clot-dissolving treatment) rate of 20 percent of patients nationally (currently 10 percent nationally).
- Increase the number of patients with a median door-to-needle time for thrombolysis of 30 minutes (now 75 minutes).
- Achieve an endovascular thrombectomy (clot retrieval) rate of 10 percent of patients nationally (currently 3 percent nationally).

Implementation

The ATN will strengthen and expand on telestroke services already in place in selected state jurisdictions. A nationally connected service will ensure a more accessible, efficient and sustainable service.

Stroke Foundation has partnered with the State and Territory Stroke Clinical Networks, and the Australian Stroke Coalition (an alliance of organisations and groups working in

the stroke field, including clinical networks, professional organisations and colleges), in support of the plan.

Deliverables

The ATN will be delivered in two phases:

- **Phase One: State-by-state roll out.** Services will connect with nearby states through shared service agreements where they do not have capacity within their own health system. For example, in Tasmania, a 24/7 telestroke is currently being delivered by Victoria.
- **Phase Two: Transition to a National Network** supported through a national agreement, spearheaded by the Federal Government. A national co-ordinating body will oversee telestroke service delivery across the country.

The following components will be essential for the roll out of the ATN:

- **Infrastructure** – This will include equipment, connectivity, and software. Of central importance is access to Computed Tomography Perfusion (CTP) diagnostic imaging. There is potential in some locations to utilise existing hardware and leverage current telehealth systems.
- **Support personnel** – A Project Manager to oversee implementation and ensure project milestones are reached. The Project Manager will undertake rostering of neurologists for the national network, ensuring that 24/7 coverage is available in all States and Territories. In addition, site co-ordinators will be needed to champion the ATN with local clinicians.
- **Local stroke awareness** – Targeted F.A.S.T. community education will be delivered concurrently in areas where the ATN will be rolled out, raising awareness about stroke and its signs and symptoms. This will ensure residents call an ambulance at the first sign of stroke, optimising access to assessment and emergency stroke treatment at telestroke sites. This will build on the community education program that is already underway.

Evaluation

A formal evaluation plan will be developed, and the service will be monitored throughout for continuous improvement. Specific measures will be devised at the commencement of the service, and could include:

- Eligible rural and regional patients with acute stroke receiving clot-dissolving treatment within the critical time window.

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- Eligible rural and regional patients with acute stroke receiving clot-removal treatment within the critical time window.
- Change in door-to-needle time (the crucial delay from emergency department arrival to treatment that is directly linked to patient outcomes).
- Calls to the service resulting in a diagnosis other than stroke (general teleneurology consultations).
- Rural and regional patients requiring transfer to a metropolitan hospital and those avoiding unnecessary transfer.
- Quantitative and qualitative feedback from metropolitan neurologists, retrieval services and country clinicians (change in confidence when dealing with complex neurological conditions) about the service.

> "City people are benefiting from amazing breakthroughs in stroke treatment but us country people are being left behind. If and how you live after stroke should not be determined by where you live. We all deserve the chance to survive and live well after stroke."
>
> **Bill Vernon**
> Survivor of stroke

The opportunity

Currently, regional and rural Australians have limited access to time-critical stroke treatment, and it is costing lives and devastating families.

There have been significant advancements in emergency stroke treatment, meaning stroke is more treatable. However, results from the 2019 National Stroke Audit Acute Services showed regional health services and their patients were being left behind.[10] Regional patients had limited access to well-established standard stroke treatments, while major city hospitals were innovating, enabling their patients to benefit from the latest breakthroughs.[10]

With the exception of Queensland, most states and territories now have pathways of care linking rural centres with comprehensive stroke centres in major cities, delivering best-practice treatment and care 24 hours a day, seven days a week.

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Now what is needed is Federal Government support for national coordination of telestroke service delivery across the country, to ensure all Australians have equal access to the evidence-based care and treatment that is proven to save lives and improve outcomes.

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National Strategic Action Plan for Heart Disease & Stroke Priority 3: Support & Care

Proposal: Mind CVD project.

Actions:

3.3.1 Ensure access to information for all Australians.

3.3.2 Provide peer and emotional support mechanisms for patients and their carers.

Investment: $425,000 over three years.

Impact: Support the 600 Australians hospitalised per day with cardiovascular disease (CVD), primarily heart disease and stroke, to be well.[11, 12] Currently:

- One in three survivors of stroke, and one in five heart attack or heart surgery patients, will develop clinical depression.[13, 14]
- One in four survivors of stroke, and one in three post heart attack and heart surgery patients, will experience anxiety.[13, 14]
- A large proportion of patients experience transient psychological and emotional distress.[15]

Implementation

The collaborative Mind CVD project addresses the need for national post-discharge psychological support and services for those recovering from a CVD event. The program aims to reduce the barriers to self-care after a CVD event that elicits depression and anxiety, and improve an individual's recovery, risk factor modification and quality of life.

The target audience for this project will be Australians who have experienced a heart or stroke event in the last 12 months, who are at greater risk of developing depression and anxiety than the general population.

The Mind CVD project proposes a multipronged approach to tackling the challenges of depression and anxiety after a CVD event, to ensure Australians have improved access to information and support for their psychological wellbeing during their recovery.

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Deliverables

- Comprehensive literature review to identify defining issues, ramifications, best care, and interventions for psychological health in CVD.
- Environmental scan and service mapping to identify psychological support services available that are proven to be beneficial for the CVD population.
- Patient support resources (co-designed with consumers) that increase awareness of psychological challenges post CVD, and provide reassurance and advice on management, support, and referral.
- Health professional resources that increase awareness of the psychological burden of CVD, and importance of screening, management, and referral pathways.
- Increased capability of Stroke Foundation and Heart Foundation helplines to provide psychological support to those living with CVD.

Evaluation

- Evaluation will be conducted for each of the resource offerings in the Mind CVD project, to measure satisfaction and impact amongst the target audience.
- Patient reported experience with helpline support will be assessed through quantitative and qualitative measurement.
- Improved screening for depression and anxiety amongst health services will be measured in targeted surveys of heart and stroke care settings.

"During my recovery, my mental health seemed to be of less importance than my physical recovery to the health professionals that were treating me, but for me it was just as important to be recovering mentally so that I could cope with the physical demands of rehab."

Clive Kempson
Survivor of stroke

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The opportunity

Good mental health is a prerequisite for physical health. The frequency of depression and anxiety varies by cardiovascular condition, but prevalence data suggests one in three survivors of stroke and one in five heart attack or heart surgery patients will develop clinical depression.[13, 14] One in four survivors of stroke and one in three post heart attack and heart surgery patients will experience anxiety.[13, 14] Depression and anxiety complicate recovery from a cardiovascular event, such as heart attack or stroke.

Despite peak body and professional society recommendations, screening for depression and anxiety is not consistently adopted in Australian heart and stroke units. When screening is conducted, follow-up support, referral and treatment is typically ad hoc and poorly implemented.

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Proposal: Stroke Journeys - Information for Aboriginal and Torres Strait Islander people.

Actions:

3.3.1 Ensure access to information for all Australians.

3.3.2 Provide peer and emotional support mechanisms for patients and their carers.

Investment: $289,000 over 1.5 years.

Impact: A step forward in the National Agreement on Closing the Gap, enabling Aboriginal and Torres Strait Islander people, and governments, to work together to overcome the inequality experienced by Aboriginal and Torres Strait Islander people, and achieve life outcomes equal to all Australians. Action will help address:

- Burden of disease for stroke in Aboriginal and Torres Strait Islander people is 2.3 times that of non-Indigenous Australians.[4]
- Aboriginal and Torres Strait Islander people are 1.3 times more likely to die from stroke as non-Indigenous Australians.[4]
- Recognised disadvantage, seeing Aboriginal and Torres Strait Islander people having higher rates of obesity, smoking, physical inactivity, and alcohol consumption – all known risk factors for stroke – compared with non-Indigenous Australians.

Implementation

Stroke Journeys - Information for Aboriginal and Torres Strait Islander people, will deliver tailored, culturally appropriate information to improve Aboriginal and Torres Strait Islander people's outcomes after stroke. The project will build on the knowledge, capacity and relationships developed through the delivery of Our Stroke Journey.

Stroke Journeys will be delivered using co-design, working in partnership with Aboriginal and Torres Strait Islander survivors of stroke, family members and carers, as well as health organisations delivering services to local Aboriginal and Torres Strait Islander people and communities.

Deliverables

- A short, easy-to-read version of Our Stroke Journey. This version will be tailored to meet different literacy, health literacy and communication needs.
- Video, audio and digital content sharing people's stroke stories. Resources will follow survivors of stroke and their families from stroke signs, to calling triple zero (000), ambulance treatment, acute care, rehabilitation and back home.
- Videos and fact sheets on stroke impacts such as emotions and mood, communication difficulties, movement and muscle changes.
- Videos, fact sheets and digital content on topics such as looking after your health, reducing your risk of future stroke, using telehealth services, getting back to work and living a good life after stroke.
- Promotion of information resources to organisations and health professionals and workers (webinars, emails, newsletters and conference presentations), and to the community (targeted free media, social media, online advertising, newsletters and radio).

Evaluation

Surveys, interviews, workshops and meetings will be used, focusing on the following outcomes:

- Reach
  - Number of printed resources distributed.
  - Number of online resources accessed.
- Satisfaction and impact
  - Feedback from health workers on the appropriateness and utility of resources, and whether they will deliver them.
  - Feedback from survivors, families and carers on the appropriateness and utility of resources, and whether they will recommend them.

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"I had constant therapy and a lot of support from my family. I wanted to be a good role model for my children, so I set goals every day. During my recovery, there were lots of tears, but there were plenty of laughs as well. I had a sense of accomplishment when my doctor said I was bouncing back quicker than expected."

Charlotte Porter
Survivor of stroke and proud Wiradjuri woman

The opportunity

The impacts of stroke are highly individual, and often complex and profound. Survivors of stroke, their families and carers need high-quality information so they can participate in their treatment and rehabilitation, manage their health, reduce their risk of another stroke and work on their recovery. To be effective, information resources for survivors of stroke need to be grounded in evidence and lived experience.

Aboriginal and Torres Strait Islander people experience stroke more frequently than non-Indigenous Australians, and are much younger when they have a stroke – 54 compared to 71 years.[16] The burden of disease and mortality is also higher for Aboriginal and Torres Strait Islander people.[4] In 2021, Stroke Foundation will launch Our Stroke Journey, the first national stroke information resource for Aboriginal and Torres Strait Islander people. During the development of Our Stroke Journey, stakeholders told us that while this resource will meet some people's needs, much more needs to be done.

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National Strategic Action Plan for Heart Disease & Stroke Priority 4: Research

Proposal: ConnectMe, an online platform to provide the critical link needed to connect researchers with the stroke community.

Actions:

4.1.1 Allocate funding for a Medical Research Future Fund (MRFF) mission reflective of heart and stroke burden of disease.

4.1.2 Allocate funding to tackle identified gaps in existing research.

Investment: $334,000 for one year (ongoing cost $8,000 per month funded by Stroke Foundation).

Impact:

- Opportunity for the almost 500,000 (non-participatory) survivors of stroke in Australia to participate in research studies.
- Leverage existing Stroke platforms InformMe (350 researchers registered) and EnableMe (8,000 community members registered).
- Lessons taken from this project have the potential for expansion across the research sector, including enhancing the AustralianClinicalTrials.gov.au initiative.

Implementation

Strengthening the AustralianClinicalTrials.gov.au initiative, ConnectMe will engage and involve stroke survivors in research as participants and collaborators, and will increase the size and diversity of research participant populations.

As an online platform, it utilises artificial intelligence, a co-design approach with researchers and stakeholders, targeted, accessible communications and innovative tools. ConnectMe will provide greater access to research trials to those who are isolated and are not able to participate through more traditional forms of recruitment.

Failing to enrol a sufficient number of subjects in a trial is a long-standing problem. Around one-third of clinical trials fail, or require an extension, because they do not meet their recruitment goals.[17]

Deliverables

- Online platform, utilising artificial intelligence, a co-design approach with researchers and stakeholders, and targeted, accessible communications and innovative tools.
- Connection with the stroke community by leveraging Stroke Foundation's two existing online platforms:
  - InformMe – utilised by more than 350 researchers to access stroke data, guidelines and resources.
  - EnableMe – more than 8,000 participatory registered users accessing support for their recovery.
- Researcher oversight from expert advisory group - including peer-review and evidence of ethics approval.
- Matching algorithm connecting researchers and participants.

Evaluation

Evaluation will focus on the following outcomes:

- Matched participants recruited annually.
- Recurring participant matches annually.
- Participant satisfaction with the project experience via an annual survey.
- Researchers registered.
- Participants registered.
- ConnectMe web-page views.
- Participants requested for research projects.
- Participants successfully recruited.
- Applications for research projects requiring participants.
- Time taken to recruit participants, per project.

- Researcher satisfaction with the project experience via an annual survey.

The opportunity

Completed, successful research is vital for informing the development of life-changing treatments received by survivors of stroke.

For research to be successfully conducted, researchers need access to a diverse, representative population. Recruitment failure can prevent research projects from commencing, leading to increased costs or termination of clinical studies.

This can be mitigated by early and targeted recruitment support.

To bridge this gap, Stroke Foundation is proposing to build an online platform - ConnectMe, to provide the critical link needed to connect researchers with the stroke community.

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Proposal: Stroke Foundation to administer a competitive research grant evaluating stroke rehabilitation services delivered via telehealth during the COVID-19 pandemic.

Actions:

4.1.1 Allocate funding for a Medical Research Future Fund (MRFF) mission reflective of heart and stroke burden of disease.

4.1.2 Allocate funding to tackle identified gaps in existing research.

Investment: $1 million over three years.

Impact:

- Almost 500,000 Australian survivors of stroke benefiting from best practice rehabilitation when and where it is needed.
- 43 percent of Australians living with stroke in regional and rural areas of Australia having access to best practice rehabilitation close to home.
- Reduction in the $6.2 billion in economic costs, and $26 billion in lost wellbeing, due to long-term disability and premature mortality, as a result of stroke.[1]
- High quality, robust research delivered and translated into practice via Stroke Foundation's living Clinical Guidelines for Stroke Management, supporting the online health professional information and training portal InformMe.

Implementation

Allied health services have experienced a significant increase in the utilisation of telehealth in response to COVID-19. With the introduction of the Medicare Benefits Schedule (MBS) item consultations in April 2020, telehealth has accounted for 20 percent of allied health consultations, and about half of the telehealth consultations were delivered through video-conferences.[18]

The use of telehealth for rehabilitation for survivors of stroke has been accelerated. We have an opportunity to see this maximised, providing all Australian survivors of stroke safe access to rehabilitation no matter where they live. We now must determine what is best-practice treatment via this medium, providing certainty for patients and clinicians, and including these findings in the Clinical Guidelines for Stroke Management.

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More than 7000 health professionals have accessed Stroke Foundation's health professional portal InformMe accessing telehealth information. New research and its translation into guidelines will provide certainty to our health professionals.

Deliverables

- Stroke Foundation will administer a competitive research grant evaluating stroke rehabilitation services delivered via telehealth during the COVID-19 pandemic.
- Overseen by the Stroke Foundation Research Advisory Committee, comprised of experienced researchers with an established track record in research on stroke and/or related fields, along with one consumer and one carer representative.
- Robust and independent review process and grant oversight, focused on impact and evidence, and adhering to a strict conflict of interest policy.
- Ongoing monitoring, accountability and support.

Evaluation

An evaluation of the impact of funded research will be undertaken by Stroke Foundation, and could include a variety of metrics, including, but not limited to:

- Number of peer-reviewed articles in which research findings are published.
- Impact factor of journals in which articles are published.
- Translation of research findings into practice, through clinical guidelines and clinician education.

The opportunity

Stroke Foundation applauds the Government for its rapid expansion of access to telehealth in response to COVID-19. Stroke Foundation and the stroke community has welcomed the Government's recent decision to partner with the Australian Medical Association to make Medicare-funded telehealth and phone consultations a permanent part of our health system.

This will help Australians to access health professionals and live well. Now we have an opportunity to see this investment is maximised.

Clinicians and the stroke community are looking for clarity in utilising these new resources. As stated, more than 7000 health professionals have accessed telehealth information on Stroke Foundation's health professional portal InformMe since March 2020. New research and its translation into guidelines will provide certainty to our health professionals.

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Proposal: Phase Two of the world-leading Living Evidence initiative.

Actions:

4.2.1 Improve research translation and availability of evidence through 'living', continuously updated clinical guidelines.

4.2.2 Develop a nationally consistent approach to support health professionals in the translation of clinical guidelines.

Investment: $8 million over four years ($300,000 annually to continue to evolve the living approach for the Clinical Guidelines for Stroke Management after the MRFF pilot concludes in July 2021).

Impact:

- Targeting an 80 percent reduction in the time from publication of relevant new research to incorporation in evidence-based guideline recommendations.
- Driving health system value through accelerated co-production of best practice recommendations based on the latest evidence targeting:
  - 50 percent reduction in time to complete key tasks for systematic review.
  - 25 percent reduction in time to update guideline recommendations to NHMRC standards.
  - 300 percent increase in the number of patients and health care professionals involved in living guideline development.
- Giving patients more opportunities and resources to be active participants in their health care, targeting:
  - 300 percent increase in the number of individuals accessing living guideline recommendations.
  - 30,000 monthly users of patient decision aids and clinical decision support tools.
- More than $1.2 billion, which is the net societal benefit of implementing new guidance within the first year of practice-changing evidence becoming available (rather than five years later), for just two interventions in stroke and diabetes.[19]

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Implementation

To enable the Consortium to build on the early success of the Phase One pilot project, and catalyse transformative change in the way evidence is generated and used in Australian health care, Phase Two of the program will be delivered through four pillars:

- **Pillar 1:** Establishing a national Living Evidence support hub: to develop best-practice methods and processes, train, support and build quality and capacity and coordinate and standardise approaches.
- **Pillar 2:** Building a Living Evidence digital technologies platform: to further develop, enhance and integrate technical systems and digital solutions, reducing unit costs and time.
- **Pillar 3:** Producing Living Guidelines: to develop and maintain living guidelines (to National Health and Medical Research Council (NHMRC) standards) for five of Australia's most high-burden diseases.
- **Pillar 4:** Getting the latest evidence to where it's needed: to optimise the dissemination and utility of evidence-based guidance and partner with Australia's leaders in knowledge translation to drive practice and policy change.

Evaluation

The Consortium will **measure and report key performance indicators** across key benefit domains to be delivered through this program:

- Rapidly bringing health and medical research discoveries to point-of-care and decision-making: targeting an 80 percent reduction in the time from publication of relevant new research to incorporation in evidence-based guideline recommendations.
- Driving health system value through accelerated co-production of best-practice recommendations based on the latest evidence:
  - Targeting a 50 percent reduction in time to complete key tasks for systematic review.
  - 25 percent reduction in time to update guideline recommendations to NHMRC standards.
  - 300 percent increase in the number of patients and health care professionals involved in living guideline development.

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- Giving patients more opportunities and resources to be active participants in their health care:
  - Targeting a 300 percent increase in the number of individuals accessing living guideline recommendations.
  - 30,000 monthly users of patient decision aids and clinical decision support tools.

> If a key piece of research is published tomorrow, we can't afford to wait 3–5 years before the impact of that research is considered.
> NHMRC (2015)

The opportunity

Technology and processes Stroke Foundation has developed and piloted (Phase One) with Cochrane Australia, as part of the Living Guidelines for Stroke Management, have enabled the Cochrane team to pivot quickly to establish a National Taskforce supporting Australian clinicians with accessible, evidence-based guidance for the clinical management of patients with COVID-19.

Living guidelines ensure clinical recommendations are streamlined, up-to-date and accessible when and where they are needed. The model has the potential for worldwide adaptation and paves the way for future innovation for a range of health conditions. Stroke Foundation is part of the Australian Living Evidence Consortium, a collaboration bringing together experts in evidence synthesis, guideline development and digital technologies, to build a revolutionary new system for delivering reliable, accessible, up-to-date evidence in health.

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Stroke innovation paves the way for COVID-19 Clinical Guidelines

Stroke Foundation applauds the Government for its investment in the National COVID-19 Clinical Evidence Taskforce.

Stroke Foundation is excited to have paved the way for world-first ‘living guidelines’ to help clinicians manage the coronavirus (COVID-19).

Technology and processes Stroke Foundation has developed and piloted with Cochrane Australia as part of a Living Guidelines for Stroke Management pilot project have been adapted. Learnings and expertise from the pilot are now being utilised to provide best practice guidelines to support doctors and nurses across the country in managing this virus.

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Alignment with Australian Government priorities

Proposals outlined in this submission support Australia's Long Term National Health Plan to build the world's best health system:

- **Pillar One:** Guaranteeing Medicare, stronger primary care and improving access to medicines through the PBS.
- **Pillar Two:** Supporting our public and private hospitals, including improvements to private health insurance.
- **Pillar Three:** Mental health and preventive health.
- **Pillar Four:** Medical research to save lives and boost the economy.

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About Stroke Foundation

The Stroke Foundation is a national charity that partners with the community to prevent, treat and beat stroke. We stand alongside stroke survivors and their families, healthcare professionals and researchers. We build community awareness and foster new thinking and innovative treatments. We support survivors on their journey to live the best possible life after stroke. We are the voice of stroke in Australia and we work to:

- Raise awareness of the risk factors, signs of stroke and promote healthy lifestyles.
- Improve treatment for stroke to save lives and reduce disability.
- Improve life after stroke for survivors.
- Encourage and facilitate stroke research.
- Advocate for initiatives to prevent, treat and beat stroke.
- Raise funds from the community, corporate sector and government to continue our mission.

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