

# Submission to the Federal Government Telehealth Nurse Navigation Consultation

## Introduction

Stroke Foundation is a national charity that partners with the community to prevent stroke, save lives and enhance recovery.

As the trusted voice of stroke in Australia we:

- Raise awareness of the risk factors and signs of stroke and promote healthy lifestyles.
- Improve treatment for stroke to save lives and reduce disability.
- Improve life after stroke for survivors by connecting them with relevant resources and support.
- 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.

Stroke is a complex chronic condition. In 2020, 27,428 Australians experienced stroke for the first time, and there were more than 445,000 survivors of stroke living in our community.<sup>1</sup> Each survivor of stroke will be impacted differently and will have different outcomes. Unless action is taken, it is estimated by 2050, Australians will experience an additional 23,000 new strokes annually, and there will be 819,000 survivors of stroke living in the community.<sup>2</sup>

As part of our [Stroke Strategy 2024](#), Stroke Foundation is committed to reaching out to those impacted by stroke to ensure more Australians can connect with and access trustworthy information, resources, and post-stroke support. **Specifically, our goal is to ensure that by 2024, 85 percent of Australians will be connected to Stroke Foundation and enabled to navigate the ongoing support they specifically need to live well after stroke, through the StrokeConnect Navigator Program.**

Stroke Foundation welcomes the opportunity to respond to the Federal Government's Telehealth Nurse Navigation Consultation. Stroke Foundation's responses to the Consultation questions are detailed below.

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<sup>1</sup> Deloitte Access Economics. 2020. No Postcode Untouched Stroke in Australia 2020.

<sup>2</sup> Ibid.

## 1. Policy Problem – What is the unmet need of patients or gap in services that the telehealth nurse-led service should be addressing?

- *Who is the target population?*
- *What is the gap/challenges that need addressing?*
- *How is the current situation impacting individuals and the health system?*
- *What evidence is available to support identified needs?*

The impact of stroke is far reaching, and well beyond discharge from hospital many survivors of stroke have yet to make a full recovery, and continue to experience neurological, physical, psychological, and social problems, including issues with memory, mobility, communication, fatigue, and pain. Mood disorders frequently occur following stroke, with one-third of survivors experiencing depression<sup>3</sup>, and between 18 and 25 percent experiencing anxiety.<sup>4</sup> Many survivors of stroke speak of falling into a ‘black hole’ once they are discharged from hospital. The often profound and prolonged brain injury resulting from stroke can severely impact a survivor’s ability to navigate an often-complex health and welfare system. This can add time and frustration to their recovery, and lead to poorer health outcomes, and hospital readmissions. Continuity of care is an issue for survivors of stroke once discharged from acute care, which has become more profound during the pandemic as a result of increased pressure on the Australian health system.

One of the major challenges to improving continuity of care for survivors of stroke is inconsistent discharge planning from the hospital system. Discharge care plans, developed with the multidisciplinary stroke team and the patient (or family), offer specific advice on a variety of areas, including secondary prevention, follow-up, and rehabilitation, and provide survivors of stroke, their families and carers, with information on relevant supports and services which exist in the community. Effective discharge care planning can reduce hospital readmission and length of stay and is crucial for successfully reintegrating survivors of stroke into the community, maximising their independence, minimising social isolation, and ensuring that the needs of the patient and carer are addressed.<sup>5,6</sup> Importantly however, 24 percent of Australian survivors of stroke are discharged from hospital without a discharge care plan.<sup>7</sup>

Additionally, the community support environment has become more complex with the deregulation of aged care services, the introduction of the National Disability Insurance Scheme (NDIS), the increasing number of service providers and the move to self-managed care. As a result, survivors of stroke, their

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<sup>3</sup> Hackett ML, Pickles K. Part I: Frequency of depression after stroke: An updated systematic review and meta-analysis of observational studies. *International Journal of Stroke*. 2014. 9: 1017-1025.

<sup>4</sup> Campbell Burton CA et al. Frequency of anxiety after stroke: A systematic review of observational studies. *International Journal of Stroke*. 2012. 8: 545-559.

<sup>5</sup> Goncalves-Bradley DC et al. Discharge planning from hospital. *Cochrane Database of Systematic Reviews*. 2016. Vol. 1, CD000313.

<sup>6</sup> Johnston SC et al. Standardized discharge orders after stroke: results of the quality improvement in stroke prevention (QUISP) cluster randomized trial. *Annals of Neurology*. 2010. 67: 579-589.

<sup>7</sup> Stroke Foundation. *National Stroke Audit – Acute Services Report 2021*. Melbourne, Australia.

carers and family members often need significant support in navigating this more complex service environment.

Four in 10 survivors of stroke will go on to have another stroke within a decade, and the risk of recurrent stroke is highest in the first year after stroke.<sup>8</sup> Without support to navigate the complex health system after they leave hospital, and access the information, resources, and services they need to recover and live well, survivors of stroke remain at increased risk of hospital readmission for complications and recurrent stroke.

## **2. Desired Outcome – What is the impact and value of a telehealth nurse-led patient navigation service to your organisation and the patients you support?**

- ***What do you want to see change as a result of a program of this nature? Consider impact on individuals, their families as well as the broader health and social care system.***

Stroke Foundation's strategic focus includes connecting more survivors of stroke with the recovery supports they need.

Stroke is a leading cause of disability in Australia. Findings from a survey of Australian survivors of stroke and their carers highlighted many survivors had ongoing complex health issues several years after stroke.<sup>9</sup> The most common health problems experienced by survivors included fatigue (78 percent), and mobility (76 percent), emotional (68 percent), memory (68 percent) and concentration (67 percent) problems.<sup>10</sup> Of the survivors who were working prior to their stroke, almost three quarters (71 percent) reported a change in their work activities since their stroke and 57 percent reported that the change was moderate to extreme.<sup>11</sup> More than one third (36 percent) of respondents reported a loss in income since having their stroke and almost half (48 percent) were receiving some form of benefit. Of those caregivers who were working prior to taking on a carer role, 40 percent reported a moderate to extreme reduction in the amount of work they were able to perform.<sup>12</sup>

The total economic cost of stroke in Australia was estimated to be \$6.2 billion in 2020.<sup>13</sup> The Federal Government bore the greatest financial and economic burden at \$2.5 billion.<sup>14</sup> This is due to lost productivity, with survivors of stroke affected by reduced employment, absenteeism and presenteeism, but also the services funded by the Federal Government, including health system costs, the National Disability Insurance Scheme and aged care services.<sup>15</sup> However, the biggest impact of

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<sup>8</sup> Hardie K et al. Ten-year risk of first recurrent stroke and disability after first-ever stroke in the Perth Community Stroke Study. *Stroke*. 2004. 35: 731-735.

<sup>9</sup> Monash University Stroke and Ageing Research Centre (STARC). 2013. Australian Stroke Survivor and Carer Needs Assessment Survey.

<sup>10</sup> Ibid.

<sup>11</sup> Ibid.

<sup>12</sup> Ibid.

<sup>13</sup> Deloitte Access Economics. 2020. The economic impact of stroke in Australia, 2020.

<sup>14</sup> Ibid.

<sup>15</sup> Ibid.

stroke is not the economic costs it causes, but the loss of healthy life. Of the total burden of stroke, loss of healthy life and wellbeing accounted for the majority at \$26 billion.<sup>16</sup>

There is a clear need for a service that reaches out to all of those impacted by stroke, their carers and families, after their return home from hospital, and ensures survivors of stroke have a smooth transition from hospital into the community. This service should facilitate improved continuity of care, and ensure survivors are connected to services and supports, and have the information they need to achieve their best possible recovery and avoid hospital readmission due to complications or recurrent stroke. This is particularly important for vulnerable survivors, and those with poor outcomes following their stroke.

**Stroke Foundation has developed a StrokeConnect Navigator Program, aimed at ensuring more Australians, regardless of where they live, are supported to manage their stroke recovery, and live well, which will have benefits for both the health system and economy.**

This Program will facilitate care coordination, including referrals to other service providers and outpatient appointments, as well as improved survivor knowledge, self-efficacy, health literacy and social connection. The StrokeConnect Navigator Program will also be focused on reducing the burden on family members and carers of survivors and improving their quality of life and physical and emotional wellbeing.

### **3. Model – What is your ideal model for the telehealth nurse-led service?**

- *What type of service is required by your target population (i.e. patient navigation; care coordination; case management; and/or health literacy)? What evidence is available to support this?*
- *Do you think a nurse-led approach is appropriate, or could this service be delivered through an alternative approach (e.g. hybrid approach with a combination of trained agent and nurse support)?*
- *What support do you think is required (e.g. peer, supervisory, clinical governance) at the patient organisation and/or program level? What are the enablers and barriers to operating a telehealth service at patient organisation level? What support do you think is required for a telehealth nurse specifically?*
- *Is there a need for a nurse to have specialist skills, or could a generalist nurse with training and access to relevant materials be suitable for this role?*
- *Do you see this service as being a single touch point, or do you think there needs to be follow-up? Why/why not? If so, how often? If you believe follow-up is necessary, is this based on previous experience and are you able to share any data that supports this? What would be the desirable hours of operation of this service?*

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<sup>16</sup> Ibid.

Stroke Foundation delivers a variety of products and services for survivors of stroke, their carers and families, including the My Stroke Journey suite of resources, StrokeLine, and EnableMe. However, based on Stroke Foundation's own existing services' data, we know there is unfulfilled demand for services from survivors of stroke who cannot easily navigate the health system after leaving hospital. For example, since January 2022, only 492 survivors of stroke have received an outreach service (outbound), and 1,912 self-referred to the helpline (inbound). This is only a small percentage of the nearly 450,000 Australians living with stroke, and the nearly 27,000 having a stroke for the first time this year, suggesting that a significant number are not accessing the support services available that could assist in recovery after stroke.

This highlights the need to develop a targeted outreach service that will enhance continuity of care through improved access to, and use of, supportive services provided by the Stroke Foundation and other community services.

Stroke Foundation has committed to augmenting its flagship StrokeLine service, building on existing capabilities to deliver a digitally enabled and enhanced, equitable, and accessible national service. The types of interventions required by the stroke community can include information, advice, care coordination and counselling.

Significant investment will enable us to extend our inbound information and support service, and implement our new continuity of care service, under the StrokeConnect Navigator Program. This will include technological upgrades, increased digital health capabilities and an additional 10 'Stroke Navigators', who will:

- Ensure the inbound service manages all enquiries in a timely and appropriate way, increasing the capacity of hospital teams as they prepare survivors for discharge.
- Deliver an equitable, proactive national outreach program to provide continuity of care and connection.

Patients with chronic and complex conditions such as stroke are also likely to require treatment and care from several different health professionals. The skills and knowledge of multidisciplinary health professional teams are critical in helping survivors of stroke manage their condition and maximise their level of functioning. Therefore, the 'Stroke Navigators' who will be responsible for delivering the Program day-to-day will be a mix of nurses and allied health professionals such as occupational therapists, social workers, physiotherapists, and speech pathologists.

As we have learned through the many years of delivering StrokeLine, it is critical for all 'Stroke Navigators' to understand stroke and the stroke support service network, to best connect the survivor with the support they need.

The StrokeConnect Navigator Program, delivered via Stroke Foundation, will offer a personalised, two-tier service, depending on the level of need:

- a tailored, self-directed digital solution for those at low risk of hospital readmission and poor physical, social, and mental health outcomes; and
- a health professional-led, intensive solution for those at medium-high risk of hospital readmission and poor physical, social, and mental health outcomes.

While some participants may only require one consultation with the service, others may require one or more follow-up consultations, depending on the complexity of the needs they have.

#### **4. Governance – How do you see the telehealth nurse-led service for your patient groups being governed, embedded, and implemented as part of a national program?**

- ***How do you think a program of this nature could be effectively and efficiently delivered? Consider the need for and value of project/clinical oversight, standardisation, networking/support and any benefits or challenges of a lead/auspicing organisation.***

As the StrokeConnect Navigator Program involves the expansion of Stroke Foundation's flagship national StrokeLine service, the key elements of this Program are already embedded in the organisation, and well established as part of the Australian stroke community. Expansion of the existing service will be critical to ensure that the service is able to focus on outreach across all Australian jurisdictions, meaning that more stroke survivors, their families, and carers will be able to access the information, advice and support services delivered by the Navigator program.

Our existing systems ensure we manage our client's privacy, can connect directly with hospitals and stroke units (for ease of referral), and our status as a national organisation means we are already a recognised and trusted voice.

With regard to Program governance, the StrokeConnect Navigator Program utilises health professionals (nurses or appropriate allied health professionals such as nurses, occupational therapists, social workers and physiotherapists) to undertake the day-to-day delivery of the Program, led by a Clinical Manager and overseen by the National Manager StrokeConnect who reports to the Executive Director Stroke Services and Research. Oversight of Stroke Foundation programs, including the StrokeConnect Navigator Program, is provided by a number of specific committees, including:

- *Stroke Foundation Clinical Council*

The Clinical Council brings together Australia's leading clinicians, academics and researchers in the area of stroke. The Clinical Council's role is to provide the organisation with a credible clinical and technical voice, as well as advice and technical support to assist with its work.

- *Stroke Foundation Consumer Council*

The Consumer Council represents the interests of survivors of stroke, carers and family members, and provides leadership in consumer engagement to achieve Stroke Foundation's mission. Members work to influence debate, advocate for the needs of survivors of stroke and carers, and to improve treatment and rehabilitation across Australia.

- *Stroke Foundation Stroke Prevention Advisory Committee*

The Stroke Prevention Advisory Committee is a sub-committee of the Clinical Council that acts within the authority of, and assists the Clinical Council to provide expert advice and input on health promotion policy, resources and program activity.

## **5. Funding/Resourcing and Sustainability - What support is required to implement a sustainable telehealth nurse-led service for your patient groups?**

- *What would be your organisations ideal model – that is, would your organisation prefer to employ a nurse directly or provide reach-back support for a nurse engaged by a lead/auspicing organisation, or an alternate approach?*
- *What other activities would need to be funded to support the objectives of the program?*
- *A key objective for the Government is to develop a sustainable model – how do you think this could be achieved?*

Stroke Foundation's ideal model would be for the Federal Government to directly fund the delivery of its StrokeConnect Navigator Program, building on the tested model and stroke support networks already in place. Stroke Foundation has allocated internal funding to enable a limited roll-out of this Program, but is seeking support from the Federal Government and State Governments to enable it to be scaled-up and rolled-out nationally, and therefore reach more survivors of stroke.

The StrokeConnect Navigator Program staffing model involves health professionals (nurses or appropriate allied health professionals such as occupational therapists, social workers and physiotherapists) who will undertake the day-to-day delivery of the Program, led by a Clinical Manager, and overseen by the National Manager StrokeConnect who reports to the Executive Director Stroke Services and Research. Adequate, long-term Federal Government funding is critical to enable Stroke Foundation to recruit and retain health professionals to deliver the Program who have the appropriate knowledge and experience in stroke, in what is an extremely competitive employment market.

## **6. Data – What data governance arrangements would you like to see implemented to support a telehealth nurse-led service for your patient groups?**

- *Evaluation will be an important element of the program to provide evidence to demonstrate the impact and outcomes of nurse-led navigation services on individuals with rare and complex diseases. What data capture would you consider essential to effectively manage the patient interaction, as well as provide evidence to assist in evaluating the program?*
- *How should data be collected and stored?*
- *How confident are you in your ability to record and store data?*
- *Does this raise any ethical concerns for your organisation?*

The Stroke Foundation StrokeConnect Navigator Program has been developed from learnings gained from evaluations of current state-based Stroke Foundation outreach services, and in partnership with research organisations. There is now significant knowledge and expertise within Stroke Foundation with regard to the development, implementation and evaluation of outreach services, and community-based health programs more broadly. Specifically, Stroke Foundation already undertakes

regular surveys of both referrers to, and participants in, state-based outreach services, for the purposes of continuous quality improvement, and funder progress reports. In addition, Stroke Foundation works closely with universities and other large research organisations to undertake more rigorous, formal evaluations of the effectiveness and impact of its programs. Data from Stroke Foundation's audits of Australian acute and rehabilitation stroke services are used to provide indirect evidence of the effectiveness and impact of its programs.

An evaluation plan for the Stroke Foundation StrokeConnect Navigator Program is under development, and key outcome measures may include, but not be limited to:

- Number of Australian survivors of stroke and their families benefiting from the Program annually.
- Participant satisfaction with the Program.
- Number of survivors of stroke receiving care coordination, including referrals to other service providers and outpatient appointments, annually.
- Degree of disability or dependence in activities of daily living, in survivors of stroke.
- Knowledge, self-efficacy, and health literacy, in survivors of stroke.
- Health-related quality of life, emotional wellbeing, levels of distress, and rates of anxiety and depression, in survivors of stroke.
- Social connection and return to work, in survivors of stroke.
- Family and carers' quality of life and physical and emotional wellbeing, and family involvement in recovery and rehabilitation.
- Rates of secondary stroke and hospital readmission.

Stroke Foundation has a comprehensive Data Governance Framework, which outlines its approach to managing the quality, usability, integrity and security of its data, including the personal and health information of individual constituents gathered through programs such as the StrokeConnect Navigator Program. Stroke Foundation also has a comprehensive Privacy Policy that sets out the standards and procedures relating to the collection, holding, use and disclosure of personal information. Stroke Foundation respects the privacy rights of all individuals and is committed to ensuring that we comply at all times with our obligations under the *Privacy Act 1988 (Cth)*, the *Privacy Amendment (Enhancing Privacy Protection) Act 2012 (Cth)*, including the *Australian Privacy Principles* and the *Privacy Amendment (Notifiable Breaches) Act 2017 (Cth)*.

## **7. Enablers/Barriers - What are the key enablers, barriers, and opportunities to support the telehealth nurse-led service for your patient groups?**

- ***What are the critical enablers for success?***
- ***What are you seeing as the critical barriers for success?***
- ***Are you aware of any specific programs or initiatives that support the patient group that could be leveraged/connected as part of this service?***



A *formal, up-to-date national register*, of all survivors of stroke who have been discharged from hospital, as well as the availability of *adequate long-term funding*, are two critical enablers that will allow Stroke Foundation to deliver the StrokeConnect Navigator Program in a sustainable way. This will have significant and long-term benefits for Australian survivors of stroke, their families and carers, as well as our health system and economy more broadly.

An analysis of areas of need undertaken by Stroke Foundation has identified the development of a targeted outreach service that will enhance continuity of care as an area of high priority. The StrokeConnect Navigator Program has been developed from learnings gained from evaluations of current state-based Stroke Foundation outreach services, and in partnership with research organisations. Stroke Foundation has allocated internal funding to enable a limited roll-out of this Program, but is seeking Government, philanthropic and donor funding to enable it to be scaled-up and rolled-out nationally. *Adequate, long-term funding* is critical to enable Stroke Foundation to recruit and retain health professionals to deliver the Program who have the appropriate knowledge and experience in stroke, in what is an extremely competitive employment market.

Currently, Stroke Foundation's state-based outreach services in the ACT and Tasmania rely on referrals from hospital-based stroke nurses, and Stroke Foundation has strong, long-standing relationships with hospitals across the country. Importantly however, this relies on the hospital teams providing the right information to every survivor of stroke, and puts the responsibility on survivors, their family members and carers, to make contact with the service. The goal of Stroke Foundation's StrokeConnect Navigator Program will be to ensure every Australian survivor of stroke is contacted following their discharge from hospital and provided with the appropriate level of information and support. Therefore, a *formal, up-to-date national register* that captures all Australian survivors of stroke once they are discharged from hospital will be a significant enabler for the success of the StrokeConnect Navigator Program, ensuring no survivor falls through the cracks.

## **8. Other feedback – Is there any additional feedback you would like to provide to inform the design of the telehealth nurse service for your patient groups?**

This video provided by one of our team, who is a survivor of stroke, sums up the experience for those who are not supported after leaving hospital. This is not a unique scenario, but just one of the many similar experiences we regularly hear about.

[Saran's video](#)

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