

Response to the Public Consultation on the Draft National Consumer Engagement Strategy for Health and Wellbeing - Online Survey Consultation Questions



Purpose

The purpose of the strategy and/or the target audience is clear?

- Not at all clear
- **Not clear**
- Unsure
- Clear
- Very clear

If not, what would make it clearer?

We agree that the purpose of the Strategy is appropriate, and is clear for policymakers; however, it may not be clear for all consumers.

As stated in the Strategy, the document has two distinct target audiences:

- government and non-government policymakers
- consumers and community organisations.

Importantly however, the current Strategy document is written primarily for policymakers, and does not address the needs of consumers. We note that the development of the document has been informed by consumers with lived experience, including consumer-led community consultations, but further work needs to be done to make this document accessible for a consumer audience. Specific strategies to consider include:

- *Using plain language*

If the document is written in plain language (or plain English) this will ensure all readers can read, understand and act on the information in the document when they first read it.

- *Making changes to the design and layout of the document*

Some practical ways to re-organise information in the document include using lots of white space and at least size 12 font, and using visuals help explain the messages found in the text.

This will ensure all aspects of the Strategy document, including its purpose, are clearer for a consumer audience.

Objectives

Are the objectives for the Strategy clear and appropriate?

- Not at all clear
- **Not clear**
- Unsure
- Clear
- Very clear

If not, what is missing?

The objectives of the Strategy are appropriate and are clear for policymakers; however, they may not be clear for all consumers. As noted above, the current Strategy document is written primarily for policymakers, and does not address the needs of consumers. Specific changes to the document, including the use of plain language, and changes to the design and layout, will ensure all aspects of the Strategy, including its objectives, are clearer for a consumer audience.

Fundamentals

Do the Fundamentals capture what you see as essential for consumer engagement?

- Not at all clear
- **Not clear**
- Unsure
- Clear
- Very clear

If not, what is missing?

We agree that the Fundamentals do capture the essential elements for consumer engagement; however, as noted above, the current Strategy document is written primarily for policymakers, and does not address the needs of consumers. Specific changes to the document, including the use of plain language, and changes to the design and layout, will

ensure all aspects of the Strategy, including the Fundamentals, are clearer for a consumer audience.

Good Practice Guidelines

Do you think the Guidelines describe what is needed to help policymakers work effectively with consumers?

- Not at all
- Very little
- Unsure
- **Well**
- Very well

Are the Guidelines explained in a way that makes them useful?

- Not at all useful
- **Useful**
- Unsure
- Clear
- Very clearly explained

Do you have anything to add about the Guidelines?

We agree that the Good Practice Guidelines describe what is needed to facilitate effective engagement between policymakers and consumers, and do not have anything further to add; however, as noted above, the current Strategy document is written primarily for policymakers, and does not address the needs of consumers. Specific changes to the document, including the use of plain language, and changes to the design and layout, will ensure all aspects of the Strategy, including the Good Practice Guidelines, are clearer for a consumer audience.

If you have been involved in policy-making before as a consumer, what made your engagement in that process:

- *A positive and welcome experience*
- *A dissatisfying experience*

Lived experience of stroke is the cornerstone of Stroke Foundation's work, and survivors of stroke, their families and carers, play an important role in many aspects of the organisation. As such, Stroke Foundation has a strong understanding of the key enablers and barriers to effective consumer engagement.

One example of how the organisation has effectively engaged individuals with a lived experience of stroke was Stroke Foundation's Young Stroke Project. Between 2019-22, Stroke Foundation was funded under the National Disability Insurance Scheme (NDIS) Information, Linkages and Capacity Building (ILC) National Information Program to deliver information for young survivors of stroke, their partners, families, friends and carers, and relevant service providers. The aim of the Young Stroke Project was to provide information to enable young survivors of stroke and their supporters to make informed choices and take action to live well after stroke. The project was co-designed and delivered with a Lived Experience Working Group (LEWG) and a Steering Group (comprised of people with lived experience and people with professional experience). The project was informed by workshops with people with lived experience and worked with people with lived experience to produce information in a range of formats – including blogs, videos, podcasts and newsletters – on topics of interest and use to young survivors of stroke. The Young Stroke website was launched in August 2022.

In 2020, a final evaluation of the project, which drew on existing documentation and data collected by the project team, and collected feedback from those involved in the project through a survey, workshops and interviews, identified a number of success factors and barriers.

Success factors

- Contributors indicated that they appreciated being able to use their experience to help others and were positive about being a part of creating a lasting resource that could support other young survivors of stroke.
- Members of the LEWG reported that they felt supported and connected, and they appreciated the safe space and commonality of purpose that they shared. Many appreciated the relationships they were able to make with others through the project, particularly valuing meeting people that 'got it' and hearing others' experiences.
- Contributors appreciated having someone with lived experience coordinate the project as this provided a lived experience perspective they could relate to and helped facilitate workshops and discussions.
- Some members of the LEWG mentioned they appreciated the flexibility of the Stroke Foundation, as this enabled them to contribute to the project in ways that worked for them. They indicated that this flexibility, as well as the strong relationships made with others, having a safe space, and commonality of purpose, enabled them to be honest.

- Members of the LEWG appreciated the option of receiving monetary compensation for their time and expertise, though some preferred not to be paid and appreciated having this option as well.
- Members of the LEWG appreciated the freedom to express their opinions and feedback on the project design.

Barriers

- Some contributors suggested the need for more information and clarity about the project, particularly in the early stages, and more frequent communication from the Stroke Foundation. Some LEWG members suggested that the meetings could have been clearer in the beginning, with a few suggesting that an external facilitator could have overseen the project and provided more guidance and direction.
- Some LEWG members mentioned that they found the co-design process challenging, and there were some different understandings, and expectations, of co-design, which was not unusual.
- Some respondents emphasised the importance of attracting more diverse contributors to the project in order to diversify its reach.

Importantly, Stroke Foundation has been able to use this feedback from LEWG members regarding specific barriers, to refine and improve our approach to consumer engagement and co-design, and this information has informed the development of subsequent projects.

Stroke Foundation welcomes the opportunity to work with the Australian Government Department of Health and Aged Care to share these learnings and our experience, and support consumer engagement throughout the policy and program development process.

HELP Toolkit

Do you think the Toolkit will be easy to use?

- Not at all
- Very little
- Unsure
- **Easy**
- Very easy

Do you think the Toolkit will help policymakers better engage consumers in policymaking?

- Not at all
- Very little
- Unsure
- **Helpful**
- Very helpful

Do you have anything else to add?

We agree that the HELP Toolkit provides policymakers with a useful resource for planning, initiating, undertaking, supporting, and evaluating consumer engagement throughout the policy and program development process, and provides a good overview of common consumer engagement approaches. We do not have anything further to add; however, as noted above, the current Strategy document is written primarily for policymakers, and does not address the needs of consumers. Specific changes to the document, including the use of plain language, and changes to the design and layout, will ensure all aspects of the Strategy, including the HELP Toolkit, are easier to use and more helpful for a consumer audience.

Are you supportive of the overall purpose, vision and aim of the Strategy?

- Yes
- **Yes, with proposed changes**
- No

Please specify proposed changes.

As noted above, the current Strategy document is written primarily for policymakers, and does not address the needs of consumers. Specific changes to the document, including the use of plain language, and changes to the design and layout, will ensure all aspects of the Strategy, including its overall purpose, vision, and aim, are clearer for a consumer audience.

Stroke Foundation is a national charity that partners with the community to prevent stroke, save lives and enhance recovery. We do this through raising awareness, facilitating research, and supporting survivors of stroke. Stroke Foundation is dedicated to empowering health professionals to deliver high quality best-practice care to stroke patients. We advocate for better systems, processes, and resources to help health professionals deliver world class stroke care.

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 - many with an ongoing disability. Unless

action is taken, it is estimated by 2050, Australians will experience an additional 23,000 new strokes annually, and there will be an additional 374,000 survivors of stroke living in the community.

As mentioned above, lived experience of stroke is the cornerstone of Stroke Foundation's work. At Stroke Foundation, individuals with a lived experience of stroke play an important role in the development of information and resources. For example, in the Young Stroke Project, mentioned above, individuals with a lived experience of stroke contributed to the development of information and resources focused on enabling young survivors of stroke and their supporters to make informed choices and take action to live well after stroke. Similarly, individuals with a lived experience of stroke play an important role in the development of targeted programs. Stroke Foundation delivers 'Living Well After Stroke', a health promotion program focused on secondary stroke prevention which aims to equip individuals with a toolkit of skills and strategies for making positive, healthy changes that last. Currently, Stroke Foundation is working with individuals with a lived experience of stroke to identify their experiences, needs, preferences and attitudes, in order to co-design a digital version of this program.

Survivors of stroke, and their families and carers, are central to stroke research. We know that when researchers and people with lived experience of stroke work together, the quality of research is better, and it is more impactful. People living with stroke are uniquely placed to help guide researchers with many aspects of their work, including study design. Lived experience of stroke is a critical aspect of Stroke Foundation's Research Program, which provides annual seed grants to support early and mid-career researchers to test their ideas, gain experience in leading a small project and tackle evidence and implementation gaps in stroke prevention, treatment, and recovery. At each stage of the Program, we listen to, involve, and engage with members of our stroke community, to ensure our research priorities address the areas that matter most to them. Stroke Foundation has also developed an online learning module for researchers on '[Working effectively with people with lived experience to design, conduct and promote stroke research](#)', which is available on InformMe, our dedicated platform for health professionals and researchers working in stroke.

As the voice of stroke in Australia, Stroke Foundation strongly supports the Federal Government's commitment to strengthening consumer engagement in the development and testing of innovative, relevant, and implementable solutions to preventive health challenges, and thus the overall purpose, vision and aim of the Strategy. Stroke Foundation welcomes the opportunity to work with the Australian Government Department of Health and Aged Care to support consumer engagement throughout the policy and program development process.

Do you have any other comments or suggestions?

A National Strategy document will typically:

- include key performance indicators (KPIs) or targets for each of its stated aims, which will ideally be specific, measurable, achievable, relevant, and time-bound to ensure their progress can be monitored appropriately
- be accompanied by an action plan detailing how the Strategy's KPIs or targets will be realised over the specific time horizon on which it is based.

The purpose of the current document is clear, namely, *to provide the information, resources and tools* needed to facilitate and support consumer engagement in the development and testing of innovative, relevant, and implementable solutions to preventive health challenges. Therefore, rather than having any specific KPIs or targets, this document is meant to serve as a resource for government and non-government policymakers and consumers and community organisations, to realise the targets and policy achievements outlined in the National Preventive Health Strategy 2021-2030. As such, it may be more appropriate for this document to be renamed the 'National Consumer Engagement **Framework** for Health and Wellbeing', the purpose of which is to support the implementation of the National Preventive Health Strategy 2021-2030.

Stroke Foundation welcomes the opportunity to work with the Australian Government Department of Health and Aged Care to support consumer engagement throughout the policy and program development process.