



# Draft National Consumer Engagement Strategy

**Asthma Australia Submission, September 2023**

## **ABOUT ASTHMA AUSTRALIA**

Asthma Australia is a for-purpose, consumer organisation that has been improving the lives of people with asthma since 1962. Asthma affects one in nine Australians or 2.7 million people. Asthma is an inflammatory condition of the airways, restricting airflow and can be fatal. There is no cure, but most people with asthma can experience good control.

Our purpose is to help people breathe better so they can live freely. We deliver evidence-based prevention and health strategies to more than half a million people each year.



## OUR RESPONSE TO SURVEY QUESTIONS

The following response starts from Q7 of the consultation survey as previous questions are for identification purposes (e.g. who we are).

### 7. PURPOSE

**The purpose of the strategy and/or the target audience is clear?** Please select only one item.

Very clear

**If not, what would make it clearer?**

N/A.

### 8. OBJECTIVES

**Are the objectives for the Strategy clear and appropriate?** Please select only one item.

Very clear

**If not, what is missing?**

N/A.

### 9. FUNDAMENTALS

**Do the Fundamentals capture what you see as essential for consumer engagement?** Please select only one item.

Clear.

**If not, what is missing?**

The following concepts are essential to effective engagement, and should be incorporated into the fundamentals:

- **Consumer engagement needs to be meaningful to consumers and they need to be able to see the relevance or importance of the issue to their lives.** This concept 'meaningful' could be embedded within the first fundamental 'purposeful' or second fundamental 'inclusive' as it is both related to consumers being able to understand and relate to the purpose of engagement, and also be able to accessibly engage with it.
- **Consumer engagement needs to value the time of consumers.** This means that engagement processes need to fit around the lives of consumers and enable them to dip in and out of consultations at various levels and times. Consumers should be invited to be, but should not



have to be, engaged from start to finish. Overly intensive or time-consuming consultations will limit feedback from only those who have the time and resources. Many consumers might have one key issue they would like to raise but might not want to be involved in a whole consultation event, and targeted approaches should accommodate this. In addition, valuing consumers' time means appropriately acknowledging the time they have given to policy/service development and ensuring it is properly resourced and remunerated. Valuing the time of consumers could sit under the third fundamental 'respectful'.

### 10. GOOD PRACTICE GUIDELINES

**Do you think the Guidelines describe what is needed to help policy-makers work effectively with consumers?** Please select only one item.

Well.

**Are the Guidelines explained in a way that makes them useful?** Please select only one item.

Very clearly explained.

**Do you have anything to add about the Guidelines?**

A key area that appears to be missing from the guidelines is the consideration of the safety and wellbeing of consumers involved in engagement processes. Policy-makers should ensure that consultation language and processes are not triggering for consumers and that appropriate supports are in place for consumers where sensitive issues or specific risks of engagement are identified.

In addition, policy-makers need to be aware of their own beliefs, judgements and values and how their involvement in the consultation process can alter the feedback and openness of consumers. This needs to be managed through training for policy-makers on using appropriate consultation methods to counter or remove their influence in the process, and on how to ensure that their views or presence does not influence or hinder consumer input when involved in consultation events.

Finally, Asthma Australia advises that the use of the phrase 'hard-to-engage' and the following phrase 'Aim to include voices normally excluded from decision-making due to a lack of engagement, active disengagement or existing barriers that prevent participation' should be reconsidered. 'Hard-to-engage' like 'hard-to-reach' places the emphasis on the consumer rather than the policy-maker so that as the lifted phrase infers fault for 'the lack of engagement' or 'active disengagement' lies with the consumer rather than the consultation process and the employment of ineffective or inappropriate consultation methods. **Instead, the guidelines could refer to 'seldom heard' groups or 'voices normally excluded from decision-making'.**



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

### A positive and welcome experience?

The elements identified for positive and welcoming engagement processes (and dissatisfying engagement processes below) are based on real experiences of our organisation and of some of our Asthma Champions and Consumer Advisory Council members.

Positive and welcoming elements of engagement include:

- **Sufficient notice and time** to be able to respond to, and be involved in, consultations. Asthma Australia responds to a wide range of government consultations and every time we respond, we aim to provide the best evidence and consumer-informed feedback. This requires the allocation of sufficient time for our feedback and involvement. For our representatives and consumers, an opportunity to choose from multiple session times, and be given regular reminders is also required.
- Widely disseminated information in and on environments that people frequently use **inviting and encouraging consumer involvement** and feedback.
- Accessible language that is easy to understand **for people of all backgrounds** and the use of terms and phrases that are meaningful to most people rather than to policy-makers (e.g. no use of policy terms, acronyms and jargon).
- Well presented issue, whereby consumers are easily able to understand it and **can see its relevance to their lives**. Consumers appreciate engagement approaches that include opportunities to learn more about how issues affect them (e.g. more about how to manage their asthma more effectively).
- Engagement approaches are inclusive and well managed to ensure all people from all backgrounds **are supported to have their say**.
- **Facilitators are well trained** and are able to make everyone feel listened to, comfortable to express their views and feel valued and included. This means facilitators are open to views that might conflict or question their own assumptions or plans and can manage group and power dynamics.
- **Open feedback on the engagement and next steps** is provided to everyone who has taken part, even when the policy or decisions might not reflect consumer preferences. Many of our Asthma Champions noted this as being an important element of previously effective engagements.
- **Consumers are appropriately remunerated/compensated** for their time and expertise. Their input is also demonstrably, including appropriate supports where necessary (e.g. support person or room for a break), to make sure all stakeholders feel respected and welcomed.

### A dissatisfying experience?

Elements that make a dissatisfying experience of engagement include:

- Online forum with **too many participants** where contributions are too hard to manage effectively.
- Facilitator has fixed views and is resistant to participants' views.



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- Engagement feels like a **tick-box exercise**, with the decision and outcome already made, and/or the perimeters of the discussion are too narrow to allow real feedback.
- Use of **jargon/inaccessible language** in documents and by facilitators.
- Facilitators and/or the environment are not welcoming. The facilitator is not well informed about the issue or does not understand it, does not manage group dynamics well or lets some contributors dominate, and/or has fixed ideas and is resistant to other people's opinions.
- **No feedback** provided by policy-makers following the consultation event.

## 12. HELP TOOLKIT

**Do you think the Toolkit will be easy to use?** Please select only one item.

Easy.

**Do you think the Toolkit will help policy-makers better engage consumers in policy-making?** Please select only one item.

Helpful

### **Do you have anything else to add?**

The Toolkit is a simple but comprehensive document and is likely to be helpful to policy-makers by giving them a basic understanding of the objectives of consumer engagement, the fundamental principles and some approaches to use. The toolkit is accessible and the use of infographics and factsheets means policy-makers will be easily able to engage with it and use it as an aid to their work.

There are a few areas where the brevity of the toolkit means that in practice policy-makers are likely to require more information/support or training to be able to implement them. For example, the Consumer Engagement Approaches are light in detail. While we strongly support the use of both indirect and direct engagement methods in helping to understand barriers to consumers engaging with preventive interventions, it is not clear how the toolkit would help policymakers decide which approaches to use and why. Some elements of this section feel randomly selected and the level and type of detail varies for every approach.

The same applies to the factsheets, which are accessible, clear and simple but they need to ensure they provide more detail, perhaps through sign-posting/linking policy-makers to more high quality in-depth resources, and they should not simply repeat the same information in different ways and textboxes. For example, the factsheet 'Monitor engagement and evaluate impact' provides some useful information, including the tips for success but as monitoring and engagement are complex areas, additional resources and tools (e.g. checklist) to help guide policy-makers through the stages of this area would be valuable. The factsheets would also benefit from the use of brief case studies, explaining previously effective consultations, when and why particular methods work and for both simple and complex issues. Case studies would help demonstrate how the theory translates into real life contexts.



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The diagrams relating to the policy cycle are helpful but the need for the first and second diagram seems unnecessary, particularly when policy-makers should be familiar with the cycle itself. Hence, only the second 'Using a Guideline throughout the policy cycle: an illustration' diagram seems to be required/helpful. The diagram on 'Good Practice Guidelines: who, what and how' needs further consideration to ensure it adds value and builds on the toolkit.

Some language used in the factsheets is not clear including who are/would be 'engagement champions' and who are the 'constituents' ('be open to learning from the constituents').

Finally, we would add the use of peer research or participatory action and ethnography as consultation approaches for place-based engagement. These consultation approaches are useful when trying to understand complex or sensitive issues and/or when working with CALD populations.

**13. Are you supportive of the overall purpose, vision and aim of the Strategy?** Please select only one item.

Yes.

**Please specify proposed changes**

N/A.

**14. If you are a consumer and haven't been involved in policy making, would you like to be?** Please select only one item

N/A.

**If you have wanted to be involved, what has stopped you from doing so?**

Some of Asthma Australia's Asthma Champions stated that they had not been involved in policy development as they were not aware of the consultations or were not invited to be involved.

**15. Are there any other engagement approaches that you have found helpful and effective?**

N/A.

**16. Do you have any other comments or suggestions?**

Asthma Australia strongly welcomes the National Consumer Engagement Strategy (the Strategy), which responds to our recommendation for its need in our submission on the National Preventive Health Strategy. We strongly support the purpose and objectives of the Strategy and their person-centred focus, which is crucial to the development of effective preventive health interventions.

The Strategy document and toolkit are well written, clear and comprehensive. They set out many concepts and approaches to consumer engagement that we support including:



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- The stated recognition of, and commitment to, the critical role of consumers, consumer organisations and communities as equal participants to preventive health partnerships.
- The stated ambition to build and sustain relational, not transactional, partnerships.
- The stated ambition not to tokenise engagement with priority groups in particular, and that partnerships need to be mutually beneficial and reciprocal.

Given the experience Asthma Australia has as an organisation in engaging with policy and service development, the Strategy is clear. However, it does use policy language, which may not be meaningful or appealing to a wider consumer audience and hence we would recommend that the Strategy is condensed to a concise factsheet for consumers. This factsheet would need to use widely accessible language and infographics to facilitate consumer engagement, and could be used as an example for policy-makers of effective engagement material. It could also be used as a way to empower consumers by understanding what best practice engagement should look like and what they should expect from policy-makers who engage with them.

Further, while we strongly support the Strategy, more detail is needed in relation to some aspects of the toolkit, including additional checklist tools and case studies to bring the guidelines to life, to ensure policy-makers can effectively implement it. The consistent use of the Strategy by all policy-makers working in preventive health is important. Hence the implementation of the Strategy and its appropriate resourcing, including of training for policy-makers and of engagement approaches, is key to its effectiveness.

