



**Lung  
Foundation  
Australia**

# **Consumer Engagement Strategy**

*Partnerships in Action*

January 2020

# Who we are

As Australia's leading lung health charity, we fund life-changing research and programs to reduce the prevalence of lung disease and cancer, and improve support and care for all Australians.

Our mission is to ensure lung health is a priority for all - from promoting lung health and early diagnosis, to supporting people with lung disease. We champion equitable access to treatment and care, and support health professionals through education and resources.

We stand for compassion, respect and collaboration, and we are fuelled by courage and driven by hope for change.

# What do we mean by consumer engagement?

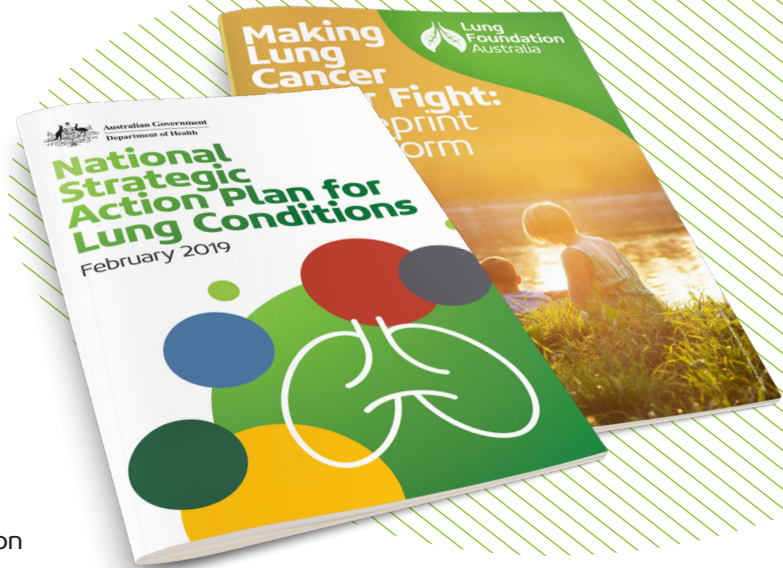
Lung Foundation Australia is committed to enhancing our partnerships with consumers, carers and families so that they are at the heart of everything we do. This strategy details how Lung Foundation Australia will actively partner with consumers. This will include activity across the areas of advocacy and awareness, research, and information and support, as well as in the planning, implementation and improvement of services. A range of partnership opportunities will be available so that consumers can decide when and how they want to be involved.

## National Strategic Action Plan for Lung Conditions

The Action Plan is the overarching plan to advance lung health in Australia. The effective prevention and management of lung disease is strongly influenced by the contributions made by a wide range of partners. These include individuals, carers, families and communities. All partners have shared responsibility for health outcomes according to their role and capacity within the health care system.

## Making Lung Cancer A Fair Fight: A Blueprint for Reform

The Blueprint is a first-of-its-kind report addressing the social, economic and mental health issues of Australians living with lung cancer. This report provides a clear indication to date of the true burden of lung cancer in Australia, now and over the next decade, and the confronting challenges facing those living with lung cancer.



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## Who are consumers?

The term consumer refers to anyone who has used health services previously, currently using health services or will potentially use health services in the future. Importantly, it encompasses their families and carers.<sup>1</sup> We are all health consumers.

For the purposes of Lung Foundation Australia's Consumer Engagement Program, we are specifically focusing on consumers with an experience across lung related diseases.

We have chosen the term *consumer* rather than *patient*, as it includes families and carers and lends itself to active and empowered individuals.

# State of play

Currently Lung Foundation Australia has a series of condition specific consumer engagement arrangements that are reactive to the task at hand. This is centred on condition specific consumer committees that each have unique terms of reference, remit and decision-making arrangements. This strategy will revise and enhance these current arrangements to build a united and strong lung health community.

## Objectives



To develop a framework that clearly articulates how Lung Foundation Australia will engage and empower consumers, carers, families and those impacted by lung disease and lung cancer.



To demonstrate a range of options and opportunities so that consumers can decide how they would like to be involved and partner with Lung Foundation Australia.



To support and build capacity for meaningful consumer engagement across key areas of activity in lung disease and lung cancer care including setting research priority areas.



To guide Lung Foundation Australia board and staff to continue to partner and connect with consumers in a meaningful way.

# The proposed framework

## Principles

This strategy is underpinned by eight guiding principles in line with the National Strategic Framework for Chronic Conditions; Equity, Collaboration & Partnerships, Access, Evidence-based, Person-centred Approaches, Sustainability, Accountability and Transparency and Shared Responsibility. The National Strategic Action Plan for Lung Conditions also adopted these principles.

## Goals

This sets out what we want to achieve and what success looks like for both Lung Foundation Australia and our partners.

1.

Lung Foundation Australia effectively communicates with and listens to consumers, carers and families representing all forms of lung disease and lung cancer. Lung Foundation Australia will take a proactive approach to ensuring the diversity of the community is represented in our partnerships.

2.

Lung Foundation Australia provides and links people to relevant, high-quality, culturally sensitive information and resources to assist them in their journey.

3.

The work and activity of Lung Foundation Australia will be guided by the priorities of our network. Consumers, carers and families will actively be involved in the design, planning, implementation and review of Lung Foundation Australia's services and programs.

4.

Lung Foundation Australia offers a range of ways and opportunities for consumers to meaningfully engage.

5.

Resources are prioritised to support consumers to develop their abilities to meaningfully engage in the national conversation about lung disease and lung cancer.

# What does this look like for Lung Foundation Australia?

- ✓ Lung Foundation Australia has mechanisms in place to deliver and receive information.
- ✓ Consumers, carers and families will be aware of Lung Foundation Australia and how it provides support.
- ✓ Lung Foundation Australia is the recognised 'go-to' for quality lung disease information and support. This will also include referral pathways and linkages to other relevant sources of information and support.
- ✓ Lung Foundation Australia has an active recruitment pathway for consumers, carers and families wanting to get involved. This will allow Lung Foundation Australia to continue to build a broad network of consumer partners that represent the lived experience of lung disease and lung cancer.
- ✓ An overarching Consumer Council will be established with representation from all forms of lung disease and lung cancer. This council will be informed by a series of disease and population specific advisory committees.
- ✓ Lung Foundation Australia staff are confident in meaningfully engaging with consumers across all facets of their work. This will involve identifying the most beneficial consumer partnership from the outset and embedding this across the process.

# What does this look like for consumers, carers and families?


- ✓ Consumers will be able to engage with Lung Foundation Australia in a way that suits them.
- ✓ A diverse range of consumers can meaningfully engage with Lung Foundation Australia.
- ✓ Consumer, carers and their family will be listened to and their story and lived experience of lung disease will be met with respect and dignity.
- ✓ Consumers will provide advice to Lung Foundation Australia, and be involved in the design, planning, implementation and review of services, resources and campaigns.
- ✓ Consumers may choose to move into a formal role within the consultative structure of Lung Foundation Australia.
- ✓ Specific training and resources are made available to build consumer capabilities in required areas, including advocacy and research.

# Evidence-based engagement

The International Association of Public Participation spectrum is useful to define the consumer role in engagement processes.

## IAP2's Public Participation Spectrum

The IAP2 Federation has developed the Spectrum to help groups define the public's role in any public participation process. The IAP2 Spectrum is quickly becoming an international standard.



	INFORM	CONSULT	INVOLVE	COLLABORATE	EMPOWER
PUBLIC PARTICIPATION GOAL	To provide the public with balanced and objective information to assist them in understanding the problem, alternatives, opportunities and/or solutions.	To obtain public feedback on analysis, alternatives and/or decisions.	To work directly with the public throughout the process to ensure that public concerns and aspirations are consistently understood and considered.	To partner with the public in each aspect of the decision including the development of alternatives and the identification of the preferred solution.	To place final decision making in the hands of the public.
PROMISE TO THE PUBLIC	We will keep you informed.	We will keep you informed, listen to and acknowledge concerns and aspirations, and provide feedback on how public input influenced the decision.	We will work with you to ensure that your concerns and aspirations are directly reflected in the alternatives developed and provide feedback on how public input influenced the decision.	We will look to you for advice and innovation in formulating solutions and incorporate your advice and recommendations into the decisions to the maximum extent possible.	We will implement what you decide.

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# How will we measure success?

## INFORM

- All information provided by Lung Foundation Australia undergoes a systematic quality check.
  - A communications plan is part of every project to ensure provision of timely information.
- The number of people interacting and receiving information from Lung Foundation Australia increases.
  - Consumers are aware of Lung Foundation Australia and are accessing its information and are satisfied with the information available.

## CONSULT

- Consumer consultation begins in the development phase of every project.
  - Standardised feedback forms are implemented.
  - Consumer feedback is considered and incorporated.
- Lung Foundation Australia has a broad network of consumer partners that represent the lived experience of lung disease and lung cancer.

## INVOLVE

- A consumer role is included in every Lung Foundation Australia project.
- The Lung Foundation Australia Consumer Council and each committee has current Terms of Reference and workplan.
  - Training opportunities are provided to consumers.
- Lung Foundation Australia staff are confident to engage and partner with consumers.

## COLLABORATE

- Training and remuneration for consumers are provided where required.
- The 2020-2025 Lung Foundation Australia strategy is developed with the consumer network and shared goals are evident.
- Lung Foundation Australia participates and supports community events.

## CONSUMER-LED

- The Consumer Council has oversight of each committee's workplan and direct line of report to Lung Foundation Australia Board.
  - Budget and resource are available for consumer-led projects.
- Challenges and successes are shared, and improvements implemented.

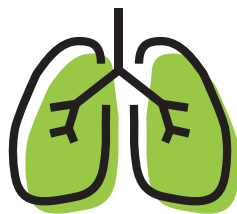
# What our network is saying?

The feedback from the consumer engagement survey provides a clear direction about how our network want to connect and be involved with Lung Foundation Australia. When asked about their connection with Lung Foundation Australia, the below responses were collected:



## What gives you hope?

- Information
- Research
- New treatments & medications
- Cure
- Support from Lung Foundation Australia



## What frustrates you?

- Loss of ability and symptoms
- Breathlessness
- Nothing
- Lack of information
- Doctors availability and knowledge



## What are your expectations?

- To live the best life
- Quality information
- New treatment updates
- Advocacy and awareness
- Slow disease progression



# Strategy in Practice

## Examples of Partnerships

### Information & support

- Provision of high-quality, evidence-based information and support to all those impacted by lung disease and lung cancer. A keen focus will be on how information and support needs differ at critical times, such as diagnosis.
- Ongoing support and connection to other useful services to live the best life with lung disease.
- Regular updates to the community on research, new treatments, medications and evidence-based treatments.
- Host education events across Australia, both face-to-face and through digital forums.

### Research

- Mechanism to facilitate connection and participation in research opportunities.
- Elicit research priorities from our consumer networks.

### Lung Foundation Australia Network

- Hold forums and workshops to identify what is important to you.
- Provide opportunities for regular feedback and input into our range of services and programs.
- Support consumers to take an active role on a Lung Foundation Australia Advisory Committee.
- Value our consumers time, effort and participation through administrative support and remuneration for travel expenses.

### Advocacy & awareness

- Provide training to increase confidence and ability to develop strategy, talk with government and media.
- Share the wonderful unique stories and lived experience of people impacted by lung disease and lung cancer.
- Provide assistance and support for grassroots fundraising and awareness events.

### Supporting documents & references

1. **Health Consumers Queensland.** *Definitions.* 2019. Available: <http://www.hcq.org.au/our-work/definitions/>

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