



Consumer Engagement Strategy 2025-2030

From passion to purpose

Introduction

Our commitment to consumer engagement

For 35 years, Lung Foundation Australia has been working to ensure lung health is a priority for all, from promoting lung health and early diagnosis, advocating for policy change and research investment, raising awareness about the symptoms and prevalence of lung disease and championing equitable access to treatment and care. We believe that to have the greatest impact we must work alongside the people who have direct experience with lung disease including a person living with lung disease, family members and carers. Partnering with our community is at the heart of everything we do, it provides us with deep insight and a genuine grounding in what it means to live with lung disease in Australia, what matters most to people and, what must be done to best support their needs.

Our Consumer Engagement Strategy (Strategy) acts as a catalyst for collaboration and confirms our commitment to providing a range of partnership opportunities so that consumers can decide when and how they want to be involved and which opportunities they feel most passionate about.

Working together will support:

- a focus on life long lung health highlighting the importance of prevention and risk factor modification
- a focus on addressing the challenges that are impacting consumers the most
- improved decision making in areas of unmet need
- enhanced effectiveness of program delivery
- significantly elevating the consumer voice to influence change through increased visibility with the community, the health sector and with our stakeholders.

Best practices supporting engagement with consumers has evolved globally

Since our first Consumer Engagement Strategy in 2020 the health sectors' understanding of how to best engage with consumers has evolved. Emphasis has grown with movement from 'participation' to 'partnership', the sector has gained deeper insights on how best to avoid the pitfalls of tokenism, it has better understood how training of consumers can strengthen empowerment, and the sector has identified a variety of ways in which consumers can engage including through advisory panels, program implementation reviews, and online communities. We also now better understand how to engage across culturally and linguistically diverse populations and how to create more supportive environments for consumers to make their voice heard.^{1,2}

Using both internal and external learnings will ensure that Lung Foundation Australia is best placed to continue to play a leading role in the sector, embodying a strong culture of engagement and continuous improvement.

What this Strategy aims to achieve

This Strategy aims to support Lung Foundation Australia in its vision of 'Healthy lungs for all', and we know that consumer empowerment is fundamental to delivering on this vision.

In this Strategy, we outline our approach to facilitating meaningful, engagement that will support Lung Foundation Australia in its work with the lung disease and lung cancer community.

¹ Australian Department of Health. (2024, September). Enhance HTA: An enhanced consumer engagement process in Australian health technology assessment - A report of recommendations. health.gov.au/sites/default/files/2024-09/enhance-hta-an-enhanced-consumer-engagementprocess-in-australian-health-technology-assessment-a-report-of-recommendations.pdf

² National Preventive Health Taskforce. (n.d.). Draft national consumer engagement strategy for health & wellbeing (NCESHW). Australian Department of Health. consultations.health.gov.au/national-preventive-health-taskforce/draft-national-consumer-engagement-strategy-for-he/supporting-documents/Draft%20National%20Consumer%20Engagement%20Strategy%20for%20Health%20%20Wellbeing%20NCESHW.pdf

Who our consumers are

Our consumers include people who are interested in lung health and prevention, those living with lung disease and lung cancer, those caring for people living with lung disease and lung cancer.

Lung Foundation Australia supports people living with lung disease together with their carers and family members.



1 in 3

Our community is one of the largest in the medical sector with **1 in 3** people having lung disease or lung cancer.



Lung cancer is Australia's leading cause of cancer death - cause of **9,119 deaths** in 2024 alone.*



In 2022-23, lung conditions collectively cost the Australian healthcare system approximately **\$13.9 billion**

(8% of disease-related health spending), more than double the costs of diabetes and chronic kidney disease combined.**



Our consumers represent disease areas including, but not limited to:

- Lung cancer
- Chronic obstructive pulmonary disease
- Pulmonary fibrosis
- Bronchiectasis
- Pulmonary arterial hypertension
- Childhood interstitial lung disease
- Occupational lung disease
- Rare lung diseases

* abs.gov.au/statistics/health/causes-death/causes-death-australia/latest-release#australia-s-leading-causes-of-death

** aihw.gov.au/reports/health-welfare-expenditure/health-system-spending-on-disease-and-injury-aus/contents/about

Goals

- 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.

Our consumer engagement approach

We believe, we are best able to serve the lung health community by developing strong partnerships with people who have lived experience of lung disease or lung cancer, and with community members who are committed to advancing lung health.

A bidirectional and interdependent partnership

We support consumers through delivering services to help improve their understanding of lung diseases, their treatment paths and the overall care outcomes. This work is underpinned by consumers who work with Lung Foundation Australia through advisory roles supporting the development of these programs and services. We work together, hand-in-hand.

How we support consumers

 **Education:** Easy to understand disease related materials, advice on best practice care, supporting mental health.

 **Community education and events:** Public events to share information, answer questions, and build relationships with consumers.

 **Social media and online platforms:** Utilise online channels to share information, engage in discussions, and build a community around Lung Foundation Australia's mission.

 **We provide a voice to government:** Advocacy campaigns, distilling the needs of the sector, seeking reform and calls to action.

 **We provide a community space:** Connecting consumers with others experiencing similar things (peer support) and enabling access to supportive professionals and volunteers.

 **We are creating a better tomorrow:** Synthesising our collective actions in research and research translation, advocacy, education and clinical settings to improve care and outcomes.

 **A trusted source of information:** Providing evidence based resources consumers can trust in language that is easy to understand, a website that is easy to navigate and user friendly access to ask us any questions they may have.

How consumers support us

 **Advisory committees:** Recruit diverse consumers to actively participate in decision-making and provide feedback.

 **Surveys and focus groups:** Gather insights and feedback on specific topics from a representative sample of our target audience.

 **Volunteer opportunities:** Invite consumers to volunteer their time and expertise to support fundraising, awareness raising and events.

 **Consumer storytelling:** Share personal stories of individuals impacted by lung disease and lung cancer and the work of Lung Foundation Australia.

 **Partnerships with consumer organisations:** Collaborate with consumer organisations that represent consumers who are aligned with lung health priorities to create collective impact.

 **Peer support:** Support trained consumers to contribute as peer mentors, support group facilitators or community connectors, strengthening lived-experience networks.

 **Data and insights collaboration:** Work with consumers to interpret insights from surveys or community data, helping sense-check themes and highlight gaps or emerging issues.



Our principles underpinning bidirectional engagement

The principles supporting our engagement processes are defined below, both for consumers as **beneficiaries** of Lung Foundation Australia's support, where we focus on empowering consumers to be active partners in their health journey within the context of Lung Foundation Australia's services and as **supporters** of Lung Foundation Australia, where we focus on how to meaningfully involve consumers in shaping our programs, fundraising, research and advocacy efforts. Achievement of our consumer engagement goals is underpinned by 10 principles which provide the foundational framework for a trusting, productive and effective partnership.

Consumers engaging as **beneficiaries** of Lung Foundation Australia services

Lung Foundation Australia → Consumer

A focus on empowering consumers to be well informed and active partners in their health journey within the context of Lung Foundation Australia's services.

- 1 Respect and Dignity:** Consumers deserve to be treated with empathy and understanding. Where diversity in background and/or health literacy level are embraced.
- 2 Information and Transparency:** Clear, accessible explanations about lung health, diagnoses, best practice care, self management and access to care will be provided.
- 3 Shared Decision-Making:** Consumers will be supported and encouraged to participate in choices about their care, with their preferences and values taken seriously.
- 4 Support and Navigation:** We will consider ways in which we can help consumers navigate the healthcare system and understand resources available to them.
- 5 Feedback and Responsiveness:** Mechanisms for consumers to provide feedback to Lung Foundation Australia will be provided with a demonstrated commitment to continuous improvement.

Consumers engaging as **supporters** of Lung Foundation Australia

Consumer → Lung Foundation Australia

A focus on meaningfully involving consumers in shaping Lung Foundation Australia's advocacy, programs, research priorities and investment.

- 1 Representation and Diversity:** Meaningful participation with representation from consumers from various backgrounds (age, race, socioeconomic status and disease severity) to reflect the population served.
- 2 Partnership:** Consumer representatives are seen as collaborators, with fair compensation and recognition for their contributions where appropriate.
- 3 Knowledge Translation:** Scientific and technical information will be communicated in clear, accessible language to support meaningful and informed involvement, and consumers' lived experiences will be respected as vital insights that guide our work.
- 4 Impact and Follow-Up:** We will define how patient insights will be used and provide updates on the tangible outcomes of their participation.
- 5 Capacity Building:** We will provide training for consumers interested in strengthening their engagement with Lung Foundation Australia and its objectives.

Our Strategy Blueprint

Our work in leading the fight for healthy lungs for all is only possible through the close partnership we have with consumers, carers, and families in the lung health community.

We invest in research, deliver support, educational programs and advocacy for the benefit of our consumers. However, our consumers are not only beneficiaries; they are also key contributors to our work, with some choosing to take on an active role in shaping service delivery.

We are, immensely grateful for this willingness to contribute and we are committed to supporting these remarkable individuals in turning their 'passion into purpose'. We do this through providing training and through providing specific engagement opportunities. This cyclical approach is known as The Circle of Impact.

Our key commitment under this Strategy is to implement four strategic priorities that will grow, strengthen and embed consumer engagement across our organisation.



The Circle of Impact

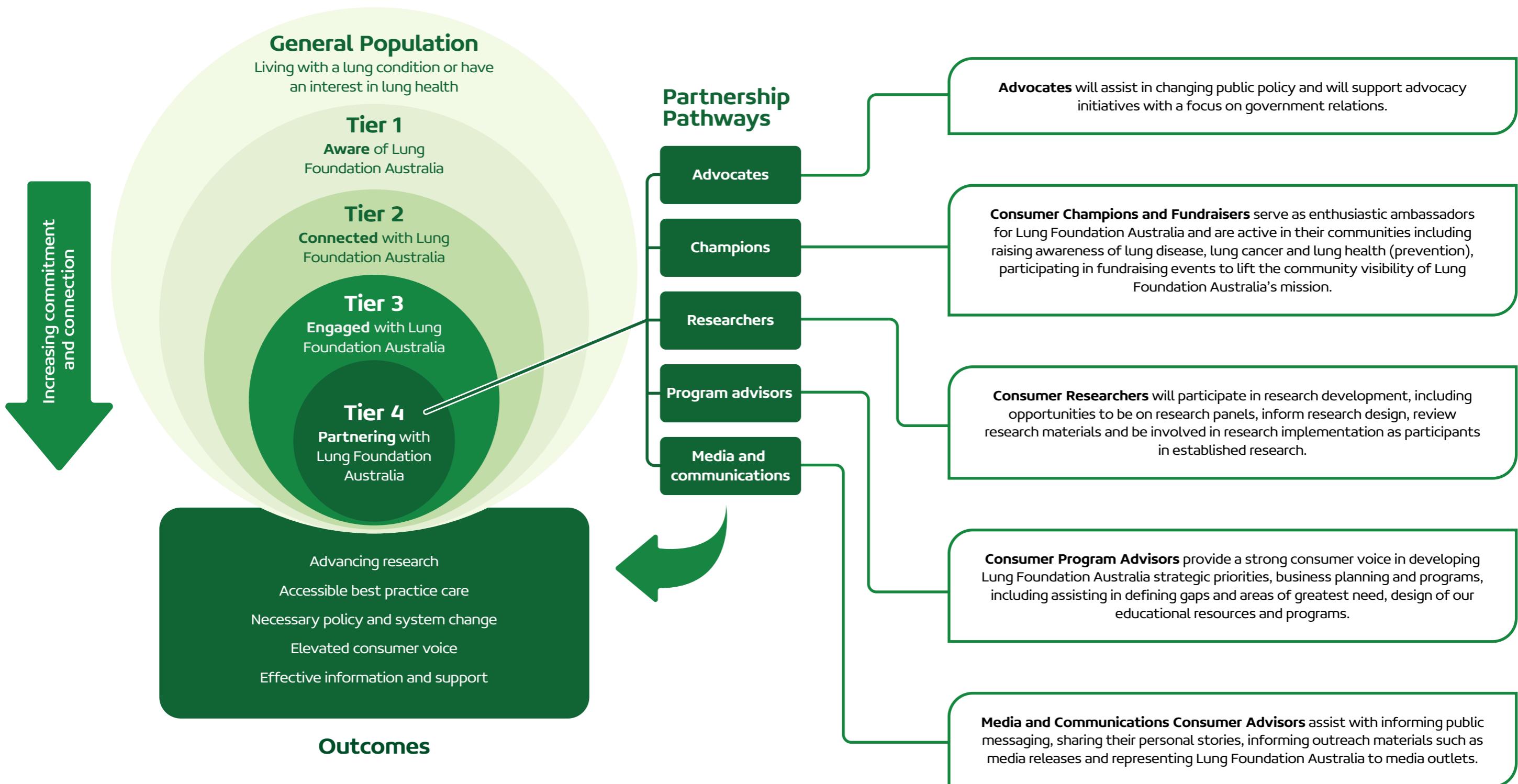


Figure 1: The Circle of Impact showing how consumers engage, benefit and influence across our operations.



Pathways to effective partnership - our model on a page

The priority areas identified by our community aligned well with our focus and are represented in the five Tier 4 partnership pathways outlined below:



Priority 1 Enabling consumers to choose their level of engagement

Our engagement with consumers has shown that not all consumers wish to engage in the same way. Consumers may interact peripherally with Lung Foundation Australia utilising resources or information (Tier 1), they may connect (Tier 2) or directly engage (Tier 3) with Lung Foundation Australia to receive information and take on specific opportunities, or they may wish to work with Lung Foundation Australia and become a trained consumer partner (Tier 4).

We will implement a tiered engagement model to better cater to the needs of each consumer.

Progression from Tier 1 to Tier 4 level of consumer engagement involves increasing commitment from both the consumer and Lung Foundation Australia with Tier 4 representing a deep partnership with mutual investment in both development and delivery.

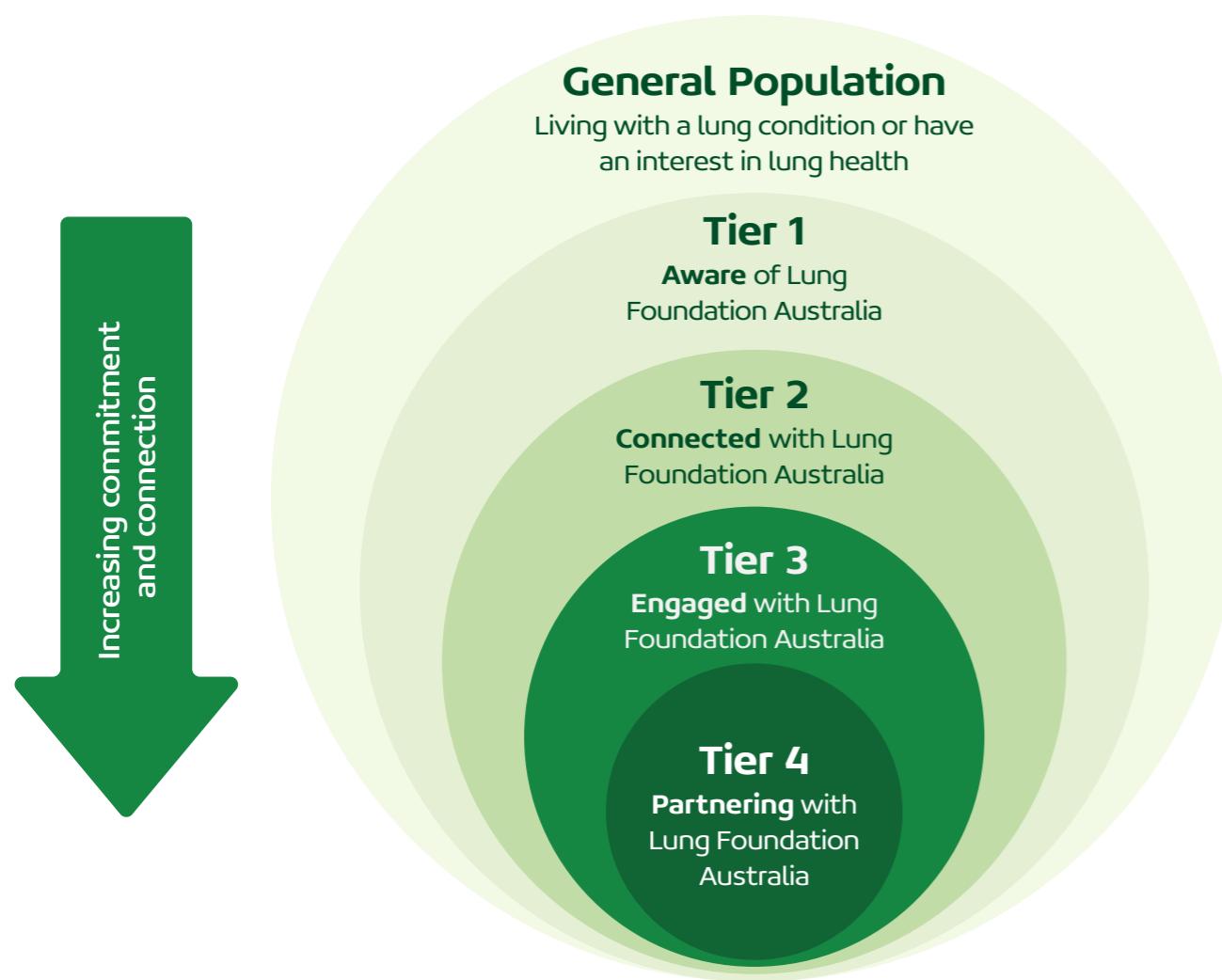


Figure 2: Lung Foundation Australia levels of consumer engagement.

Priority 2 Enabling consumers to choose their form of engagement

Connecting passion with a purpose enables our consumers to be effective and to enjoy their work with Lung Foundation Australia. The tiers outlined in the engagement model enable engagement at all levels.

We listened to our community to understand in what ways they wanted to partner with Lung Foundation Australia. Recent lived experience work has helped identify and further strengthen our understanding of how people living with a lung condition would like to be involved (Figure 3).

- **General population** – Our **broad community of interest** - people living with lung disease and lung cancer, care givers, and people who have an interest in lung health and prevention
- **Tier 1** – Consumers **aware** of Lung Foundation Australia and who have accessed our information but not yet connected to us
- **Tier 2** – Consumers **connected** to Lung Foundation Australia for information and program support
- **Tier 3** – Consumers who are more deeply **engaged** with Lung Foundation Australia and seeking further opportunities to contribute
- **Tier 4** – Consumers **partnering** in our work and supported to contribute

We will support consumers to engage in ways that are meaningful to them.



Figure 3: How people living with a lung condition would like to help (McLaren, R Haszard, D) *The Lived Experience 2024 Research Report – Lung Foundation Australia*, July 2024, unpublished.

Priority 3 Enabling consumers to develop and supporting their empowerment

Our consumers bring a wealth of lived experience. Many however have expressed the desire to access training to lift their capacity to impact. Training can support consumers to be the voice for their communities, it can build understanding of research and program administration, it can also support other skill development activities such as those related to research, public speaking or resource development.

Lung Foundation Australia will establish a Consumer Academy. This new initiative will house consumer training materials and resources, centralise management of training and promote a sense of community. Lung Foundation Australia's Consumer Academy will create a recognisable brand and identity, and further demonstrate our ongoing commitment to advancing engagement with our consumers.

We will create a Consumer Academy that will support the training needs of our consumers.

Priority 4 Understanding the effectiveness of our engagement, responding to our consumers' needs and adapting where required

With an improved system which better supports the engagement and training of our consumers we expect that we will be able to better meet the needs of our community. Advocating, fundraising, championing, researching and delivering programs that support care outcomes for those with lung disease.

Through engagement we will learn and in doing so identify new opportunities - the process will be dynamic and we will be responsive, adapting our approach to ensure consistent alignment with our consumers.

We will determine how the measures outlined in this Strategy have supported the engagement of consumers and contributed to our work to seek continuous improvement.

Moving forward together

Building on the foundations of our earlier work we define here our Strategy for strengthening our partnerships with our lung health community - we are excited to put this Strategy into action. This will mean creating clear pathways for working with our community, defining roles, launching our Consumer Academy to support the training needs of our consumers, and establishing ways to measure our success.

Through this Strategy we show our continued commitment to respecting the voice of our consumers and to finding better ways to integrate advice from our consumers with the expertise provided through our scientific and clinical subject matter experts, our executive and program staff, and our broader stakeholder network.

If we do this effectively, connecting passion to purpose, we believe we will be better at supporting improvements to the quality of care for those living with lung cancer and lung disease.

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**Lung
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