



National Pulmonary Rehabilitation Strategy Framework 2023 – 2026

Ensuring pulmonary rehabilitation is accessible, affordable, impactful



Lung Foundation Australia is Australia's leading peak body for respiratory health and lung disease. Lung Foundation Australia funds life-changing research and delivers support services to enable Australians with lung disease including lung cancer to live their best lives.

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Lung Foundation Australia would like to acknowledge Roche who contributed an untied grant to support the development of the National Pulmonary Rehabilitation Strategy 2023 – 2026. Please note that consistent with Lung Foundation Australia policy, LFA and the expert steering committee maintains its independence over all facets of this publication and the associated planning.



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Lung Foundation Australia
PO Box 1949 Milton QLD 4064
Tel: 07 3251 3600
Email: enquiries@lungfoundation.com.au

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“Pulmonary rehabilitation gives you the knowledge, positivity and strategies to do more. It’s a life-time skill that you implement every day”.

- Sharon, Melbourne VIC



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Lung Foundation Australia acknowledges the Traditional Custodians of the lands on which we work throughout Australia and their unceded sovereignty of and continuing connection to land and sea. We pay our respects to their cultures and to Elders both past and present. We acknowledge the overrepresentation of Aboriginal and Torres Strait Islander Peoples in lung disease and lung cancer. In the spirit of reconciliation, we recommit to working with communities to close the gap on lung health and build on the strengths of communities to lead and guide the path to healthy lungs for all.

Forward

There is limited availability of Pulmonary Rehabilitation (PR) for the number of people with eligible lung conditions resulting in many of those who could benefit from PR, not receiving this evidence-based service (AIHW et al. 2013; Lee et al. 2021; Rochester et al. 2013; Stout et al. 2020). In Chronic Obstructive Pulmonary Disease (COPD), one of the conditions most commonly referred for PR, uptake is estimated to be only 5-10% of people who could benefit from the intervention (AIHW et al. 2013; Brooks et al. 2007). This is related to lack of availability of local programs, transport issues, long waiting lists, poor referral rates and poor consumer knowledge of benefits and uptake of existing programs.

There is also inequity of availability of PR throughout Australia especially for Aboriginal and Torres Strait Islander Peoples, Culturally and Linguistically Diverse (CALD) and rural and remote communities.

Of 977 people living with a lung condition who completed Lung Foundation Australia's Lived Experience Survey in 2020, only one in three had ever seen a PR therapist or a respiratory physiotherapist and 40% felt that PR programs were not easily accessible.

In response to the question 'What would encourage or support you to attend a pulmonary rehabilitation program' one respondent wrote:

"Knowledge that [PR] existed in the first place, and referral by health care providers."

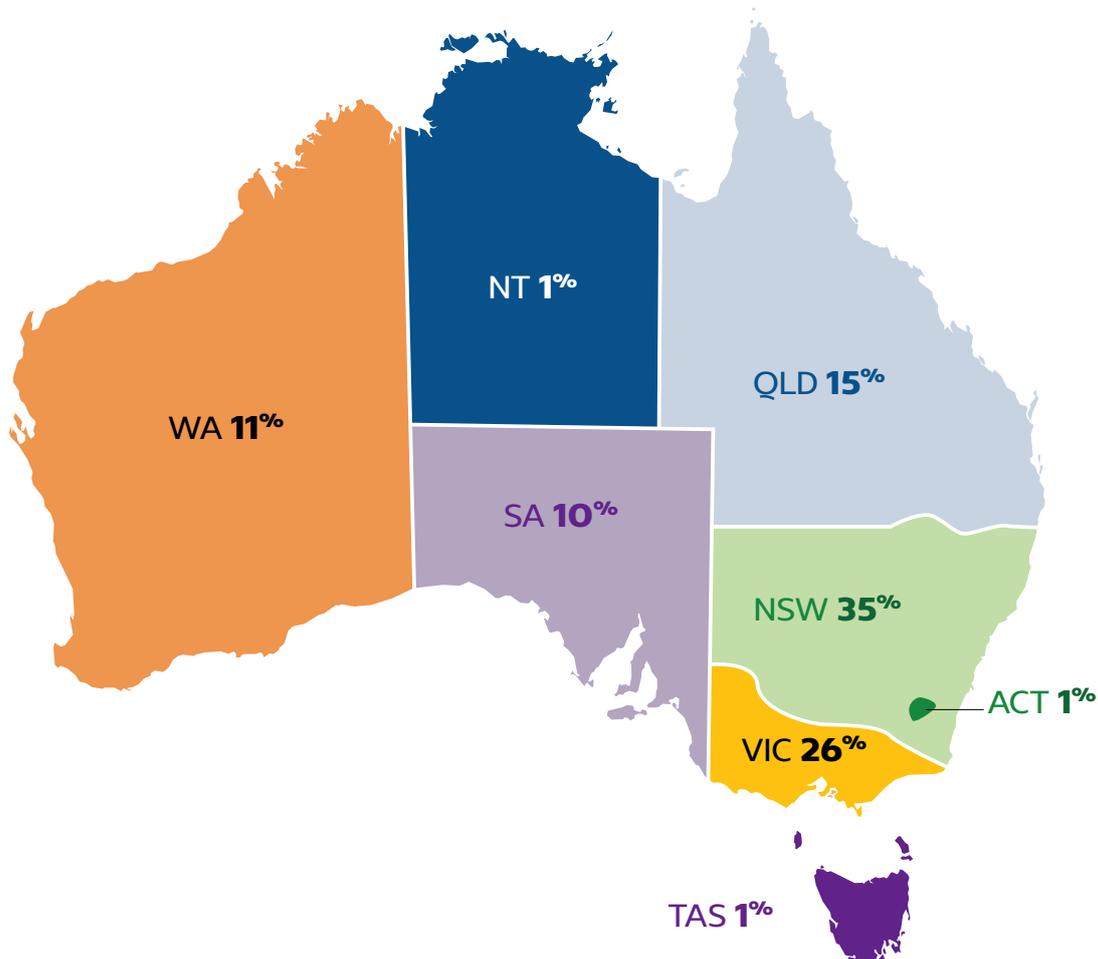


Fig 1: 2022 National Audit of Pulmonary Rehabilitation – Lung Foundation Australia
Distribution of PR programs across Australia (n=323)

Since the COVID-19 pandemic, new health concerns have risen for many Australians who are experiencing post-acute symptoms, such as breathlessness (Lung Foundation Australia 2022). Through exercise and self-management education, PR may be effective in supporting people with ongoing COVID-19 symptoms and in COVID-19 recovery. Additional places in PR programs need to be funded, to enable increased capacity to provide rehabilitation for people with continued respiratory symptoms after COVID-19 infection and to ensure equitable support for Australians regardless of their location and financial position.



“[I had] reduced exercise tolerance and ability to work as much or exercise as much. Support for people with long COVID. Fear of the future, if I can no longer work full time. Loss of enjoyment of life due to fatigue and breathlessness.”

- QLD resident who had COVID-19

Throughout 2022/23 Lung Foundation Australia worked with a dedicated group of Key Opinion Leaders (KOL) (Appendix 1) to develop a National Pulmonary Rehabilitation Strategy to determine the key action areas to support increased access and equity of PR throughout Australia.

The process involved validating the key priority areas with representatives from the broader Pulmonary Rehabilitation Network (PR Network) and a panel of consumers to ensure the strategy meets the needs of health professionals and consumers.

This document outlines the key action areas as identified (Image and awareness; Data and service quality; Access; Funding), along with the activity needed to address these issues. The strategy includes the success measures and outcomes that will be achieved through the implementation of the strategy.



Executive summary

The four key action areas

Four key action areas were identified: Image and awareness; Data and service quality; Access; Funding.

1 Image and awareness

The issue:

PR has a public relations challenge that needs to be addressed.

PR is a multidimensional intervention incorporating exercise, education and psychosocial support (AIHW et al. 2013) and can benefit people with chronic lung conditions at various stages in their lung health journey, from when they are first diagnosed to after a hospitalisation for an exacerbation, and as part of an ongoing management plan.

Consumers and some health professionals have misconceptions around PR, with no clear understanding of what is involved, who can benefit and what the benefits are from the program. This misunderstanding of PR limits investment, referrals, interest, and access to PR programs. PR is often considered to be a palliative intervention for people who are too sick to make improvement. There is also a perception that PR is only required after an exacerbation or hospital admission or that it is only for the elderly or those with severe disease. In contrast, some consumers think that PR is only for those who are still physically capable.



“People think that you need to have had a serious life-threatening event to be doing rehabilitation. They don’t understand all the wonderful positive advantages of PR.”

- Sharon, Melbourne VIC

GOAL: The goals of the **Image and awareness key action area** is three-fold:

1. For consumers to understand what PR is and how it will help them manage their condition and improve quality of life at different points in their lung health journey.

2. For health professionals to be aware of the evidence regarding benefits of PR in various lung conditions and understand how to refer consumers into a program.
3. For decision makers to understand and consider the benefits of PR and the health, social and financial benefits of investing in it.

2 Data and service quality

The issue:

There is a lack of consistent Australian data around the outcomes and impacts of our PR programs. A robust data set will provide a strong evidence-base and enhance benchmarking for understanding and reducing variations in care to ensure quality service provision and continuous quality improvement. A real time data gathering solution which will provide service outcomes and information on effective models of delivery nationwide is required.

GOAL: Establish national standard outcome measures for PR. Develop real-time data gathering systems to evaluate outcomes of PR programs against national standards.

3 Access

The issue:

There is an inequity in the availability of PR throughout Australia especially in Aboriginal and Torres Strait Islander Peoples, CALD and rural and remote communities. There are a limited number of PR programs and it is known that cost and transport can be a barrier for consumers to attend. Establishing new PR programs should be prioritised in areas of high disease-burden and/or where service gaps exist. Service providers need to acknowledge that one size does not fit all and that there is value in considering alternative models of PR delivery (e.g., telerehabilitation or home-based). PR becoming more available in primary care settings through new funding models, would serve to compliment existing hospital services, making PR more accessible, particularly for consumers in rural and remote

locations and Aboriginal and Torres Strait Islander Peoples accessing health services through Aboriginal Community Controlled Health Services. A standardised referral process is needed to streamline uptake of PR.



“People in rural areas are often overlooked when it comes to medical services. It is VERY expensive to travel and stay in accommodation in the city and it is physically exhausting.”

- Consumer Survey Respondent, Lung Foundation Australia 2023

GOAL: For all consumers to have access to high-quality PR programs regardless of their location and ethnicity.

4 Funding

The issue:

For service access to improve, PR needs to be made commercially viable for primary care health professionals to deliver it. In addition, we need to engage with state and federal health departments for increased funding to recruit more healthcare services to deliver PR in regional and remote communities and strengthen the financial base of existing centre-based programs. We need to ensure equity in our service offering and consumer outcomes.

GOAL: Increased funding for PR through local and government initiatives.

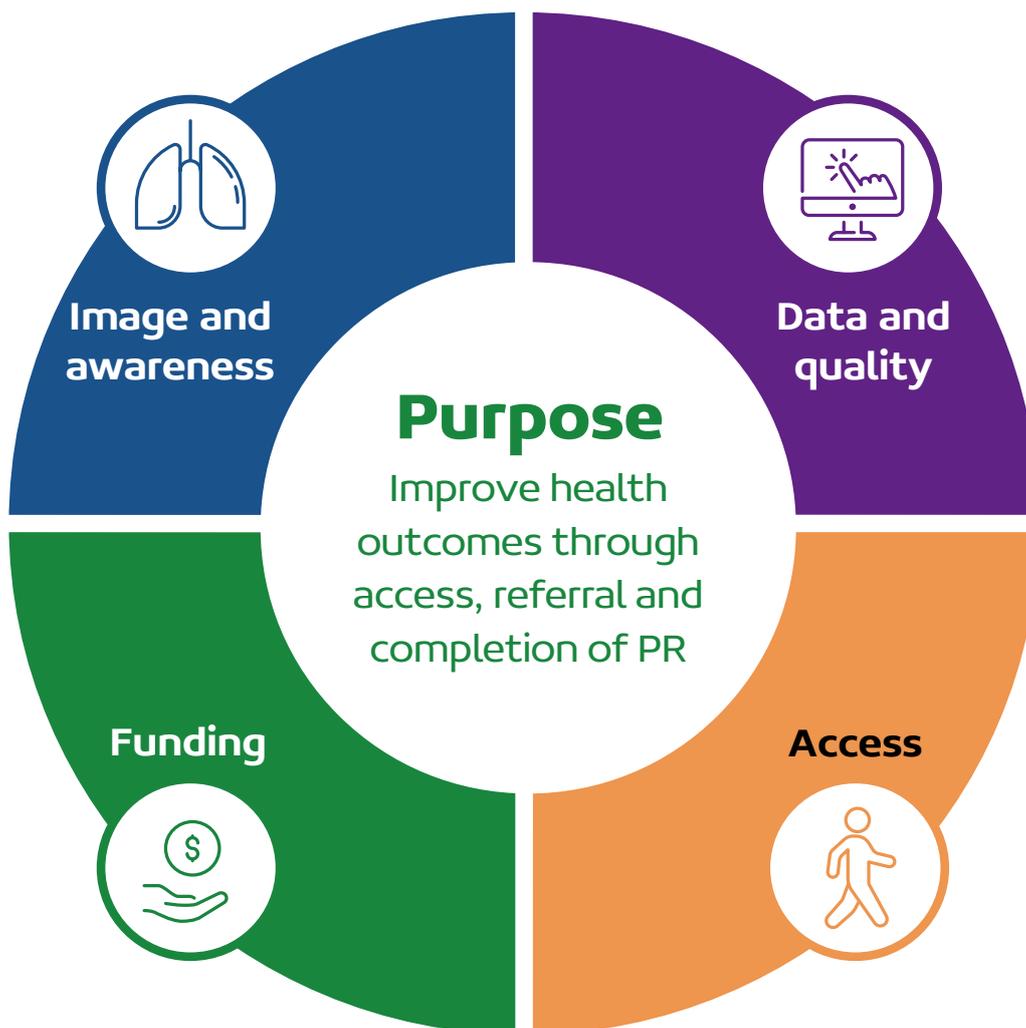


Fig 2: 2023 PR key action areas

Background and introduction

Lung Foundation Australia is the only national charity dedicated to supporting all Australians with a lung condition. We are a national first point-of-call for consumers, their families, carers, health professionals and the general community. Our primary objectives are to reduce the impact of lung conditions in Australia by promoting lung health, facilitating early diagnosis and access to evidence-based care, providing support to those affected by lung conditions, and by promoting quality research.

PR is a six-to eight-week, evidence-based, exercise and education program that teaches people with a chronic lung condition the skills they need to manage their breathlessness and stay well and out of hospital. The program consists of an individual assessment which includes medical history and testing of exercise capacity in a safe environment, followed by a program of exercise training and education. The exercise training component focuses on increasing physical function and is individualised so that it is appropriate and safe for each person. The education component assists consumers to manage their condition by providing knowledge in areas such as breathing techniques, use of medications and energy conservation (Alison et al. 2017).

PR is recognised in Australia and across the world as the most effective non-pharmacological disease management intervention which provides a magnitude of positive health outcomes for those living with a chronic lung condition, including but not limited to, increasing overall quality of life, increasing functional exercise capacity and reducing symptoms of breathlessness and fatigue (McCarthy et al. 2015). Additionally, PR reduces hospital admissions and length of stay, and reduces re-admissions post exacerbations (Jenkins et al. 2024). These factors are not only important for the consumers but have considerable positive benefits for the economy and health system by reducing costs.



“Low investment and awareness persist, driven by pervasive misconceptions that rehabilitation is too costly, or simply unfeasible to deliver in low-resource settings.”

- WHO, Package of interventions for rehabilitation 2023

In Australia, PR is included in the Australian and New Zealand COPD-X Guidelines for the management of COPD as the most important non-pharmaceutical intervention to optimise function (Yang et al. 2016). This highlights the high acceptance of PR. Furthermore, the first Australian and New Zealand PR guidelines were published in 2017, further highlighting the importance of this effective treatment (Alison et al. 2017) and resources to support clinicians to establish evidence-based PR programs.

PR can be provided in hospital outpatient departments, in community facilities or at home. Community-based or home-based PR programs or telerehabilitation using videoconferencing that include regular contact with a health professional to facilitate exercise participation and progression, can be offered to people with chronic lung conditions if centre-based programs are not available or accessible or if the PR providers are able to give participants a choice of program mode. Importantly, these modes of delivery should include exercise training at an equivalent intensity, duration and frequency as centre-based PR programs.

COVID-19 implications to PR

Since the coronavirus outbreak in 2020, PR has experienced a huge disruption to services. Given the highly vulnerable nature of participants, many services were forced to temporarily shut down or move to an online format as a contingency measure. As a result, many services may now have longer wait lists and patients' conditions may have become more complex with comorbidities by the time they are seen.

Lung Foundation Australia conducted an audit of PR programs in 2022 and found that a large number of programs were now supporting consumers recovering from COVID-19 or experiencing long COVID symptoms.

Consumers Recovering from COVID-19



69% of services supported patients who have been in hospital due to COVID-19



59% of programs supported patients with long COVID

Fig 3: 2022 National Audit of Pulmonary Rehabilitation - Lung Foundation Australia
Consumers recovering from COVID-19



Lung Foundation Australia's advocacy journey

Since 2013, Lung Foundation Australia has undertaken a significant amount of work to support a sustainable funding model for PR (Appendix 2) including one unsuccessful submission to the Medical Services Advisory Committee (MSAC). This application proposed a series of new Medicare Benefits Schedule (MBS) item numbers to address a much-needed gap in service provision. As part of our 2017 revised submission, MSAC commissioned Deloitte to conduct a full economic and health needs analysis. Their findings were positive, demonstrating compelling evidence for the health and economic benefits for COPD patients. They did however, report that there was more limited evidence for Interstitial Lung Disease (ILD) and inadequate evidence for bronchiectasis in improving exercise capacity. The 2022 PR Audit, led by Lung Foundation Australia, showed that 89% of services now accept people with many different chronic lung conditions as well as COPD, compared to 43% in 2017 (Appendix 4). This expanded provision of services for more people with chronic lung conditions strengthens the case for increased funding for PR.

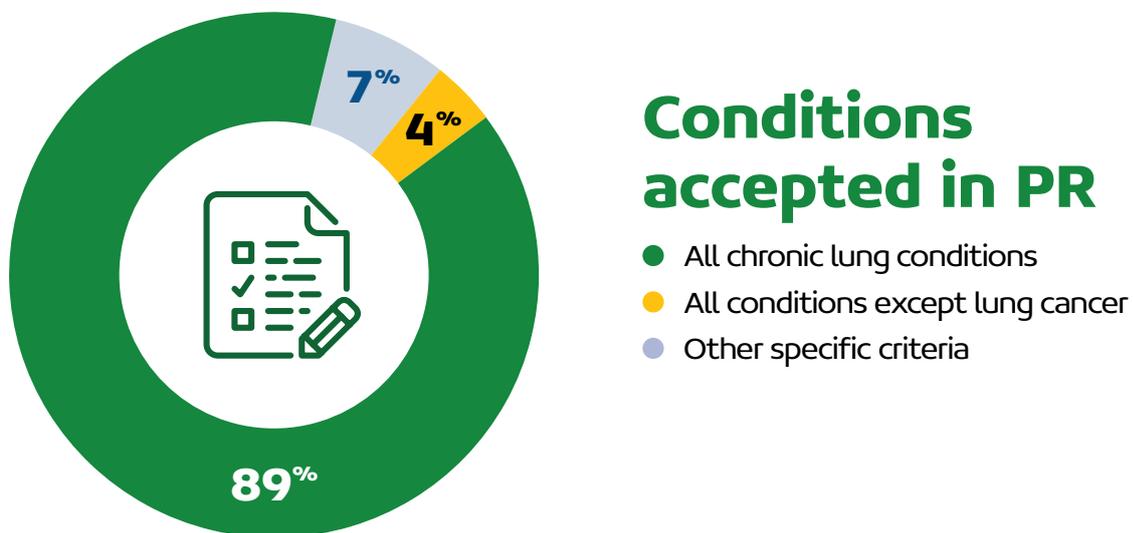


Fig 4: 2022 National Audit of Pulmonary Rehabilitation - Lung Foundation Australia
Conditions accepted in PR

Along with a dedicated team of expert clinical and academic supporters, Lung Foundation Australia is committed to progressing this work, **and is calling on the Australian Government to make a funding commitment to support this evidence-based intervention which has been shown to keep people well and out of hospital.**

The 2023-2026 National Pulmonary Rehabilitation Strategy Framework Project

As a continuation of this vital work, in 2022 Lung Foundation Australia brought together KOLs in PR to determine the strategic priorities to develop a three-year national PR Strategy Framework. The multidisciplinary KOLs included a range of clinical and academic experts who specialise in supporting a variety of consumer cohorts including those with COPD, ILD, bronchiectasis, pulmonary hypertension, lung cancer and long COVID (Appendix 1).

The KOLs articulated the benefits for PR and why it is critical for PR to be included in the pathway of care for people living with a lung condition. The KOLs examined the evidence and benefits for PR beyond just COPD in conditions such as lung cancer where survivorship is increasing. The group determined the areas where more needs to be done to improve access, equity and quality of PR programs across the country.

A PR Network Symposium was also held to engage the broader sector of health professionals and to seek their opinion and input into the areas of need and the opportunities for improvement. The PR Network Symposium was key to engaging PR stakeholders as a 'coalition of the willing' who will become champions of the action plan that is developed through this strategy.

The process (outlined in the diagram below) began with a broad questionnaire to gauge the most important priority areas for which to advocate. An initial KOL session was held to discuss the why, what and how of our advocacy approach and the viability of another MBS item application for PR. The PR Network Symposium was held with the broader PR Network in May 2023 to capture feedback on the action plan developed at the KOL session. Lung Foundation Australia also held a Consumer Engagement session to enable consumer input into the PR strategy document. The process ended with a final regroup of the KOLs to assess and integrate the outcomes of the PR Network symposium and Consumer Engagement session.

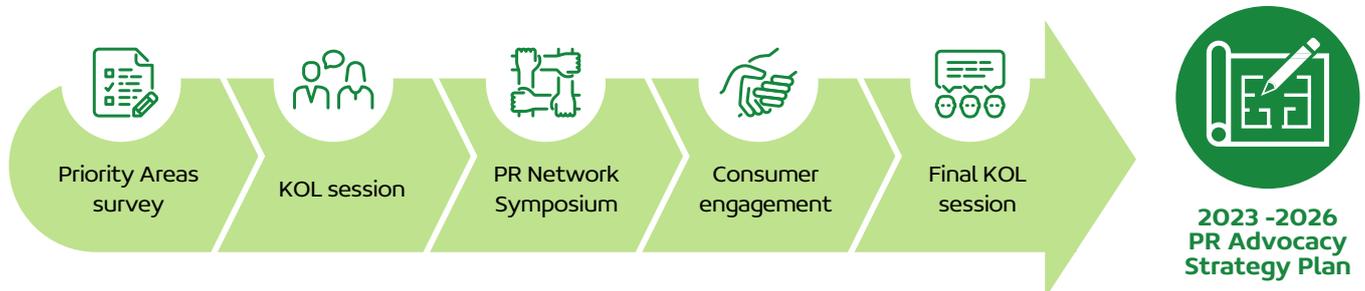


Fig 5: Phases of development for the PR Strategy Framework

Strategy context

In 2019, the Department of Health National Strategic Action Plan for Lung Conditions (The Action Plan) was published to provide a detailed, person-centred roadmap for reducing the individual and societal burden of lung conditions and improving lung health. The Action Plan identifies the need to increase funding and access to PR in the community and home setting with a focus on regional, rural and remote communities, upskill and accredit PR programs and practitioners and provide culturally safe and accessible PR programs for Aboriginal and Torres Strait Islander Peoples.

The Australian Commission on Safety and Quality in Healthcare (ACSQH 2024) is developing the first COPD Clinical Care Standards. These standards will aim to ensure that people receive best-practice care for COPD, regardless of where they are treated in Australia. The standards will highlight that health services should ensure that systems, processes, and resources are in place to support referral and access to pulmonary rehabilitation programs for people with COPD.

This PR strategy sits within a broad health policy environment that includes respiratory and lung health, preventive health and chronic conditions, and policies focused on improving the health workforce, healthcare systems, and outcomes for Aboriginal and Torres Strait Islander Peoples and other populations with unmet needs. It aligns with key national policies and strategies, including:

- National Strategic Action Plan for Lung Conditions
- National Preventive Health Strategy 2021-2030
- Australia's Long Term National Health Plan
- National Strategic Framework for Chronic Conditions (draft)
- National Aboriginal and Torres Strait Islander Health Plan 2021-2031
- National Agreement on Closing the Gap
- Australia's Primary Health Care 10 Year Plan 2022-2032
- Stronger Rural Health Strategy
- National Nursing Strategy (scheduled for completion in 2023)
- State and Territory Policies and Strategies on Chronic Conditions
- ACSQH Chronic Obstructive Pulmonary Disease Clinical Care Standards, Quality Statement 4 Pulmonary Rehabilitation (draft).

The 2022 PR Audit

In 2022, Lung Foundation Australia undertook a national audit (survey) of PR programs to gather data on the various delivery modes, referral criteria and other relevant details including the impact of COVID on PR programs (Appendix 4). The survey was distributed to 320 PR programs registered on Lung Foundation Australia’s PR program service directory. The total number of programs that provided a complete response to the survey was 169 (52% response rate).

The figures below provide an overview of key findings from the survey, including referral pathways, lung conditions accepted, program components and service models in operation. Whilst it is heartening to acknowledge that 89% of programs now accept consumers with any type of lung condition, including lung cancer (43% increase compared to the 2017 PR Audit), there is clear inequity in the national distribution of PR programs compared to the distribution of the population and disease burden across Australia, in particular in NT and TAS.

The survey findings indicated that a range of self-management and disease-specific education topics are provided in PR programs, in combination with an exercise program, which is consistent with the acknowledged key components of PR (Spruit et al. 2013).

Whilst 46% of respondent programs indicated that they do accept self-referral by consumers, it is acknowledged that health professionals (84% GPs and 51% health specialists) remain the main driver for referral to programs. This emphasises the importance of increasing awareness and understanding of PR among Australian health professionals and ensuring that referral pathways are accessible and streamlined to maximise the opportunities of consumer access. Health professionals also need to be aware of the availability of alternative modes of delivery of PR, such as telerehabilitation or home-based rehabilitation, in addition to traditional centre-based formats. These alternative models of PR may enable better access to PR for some patients.

Distribution of PR programs across Australia

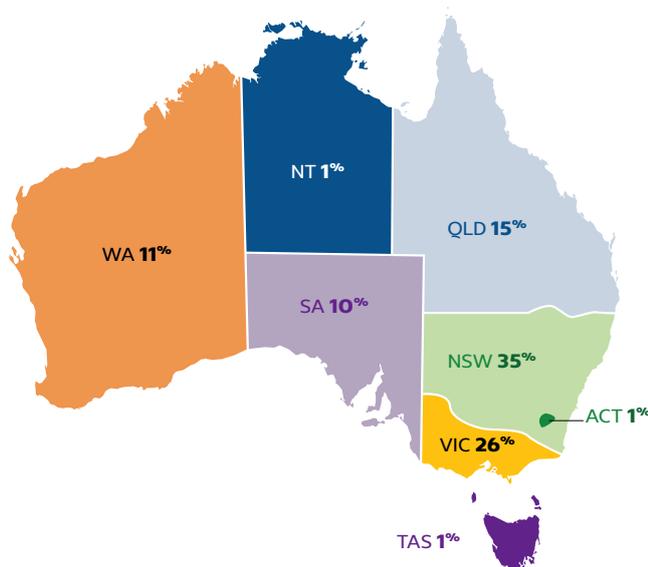
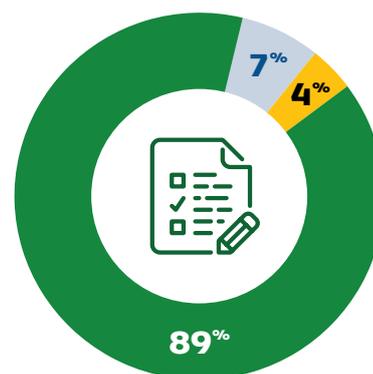


Fig 1: 2022 National Audit of Pulmonary Rehabilitation - Lung Foundation Australia
Distribution of PR programs across Australia

Conditions accepted in PR



- All chronic lung conditions
- All conditions except lung cancer
- Other specific criteria

Fig 4: 2022 National Audit of Pulmonary Rehabilitation - Lung Foundation Australia
Conditions accepted in PR

..... **Types of education sessions offered in a pulmonary rehabilitation program**

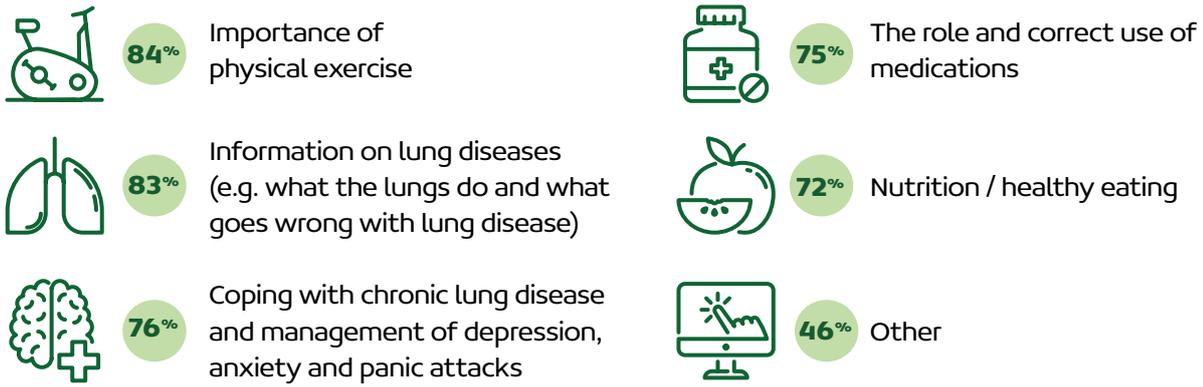


Fig 6: 2022 National Audit of Pulmonary Rehabilitation - Lung Foundation Australia
Topics covered in education sessions in PR programs

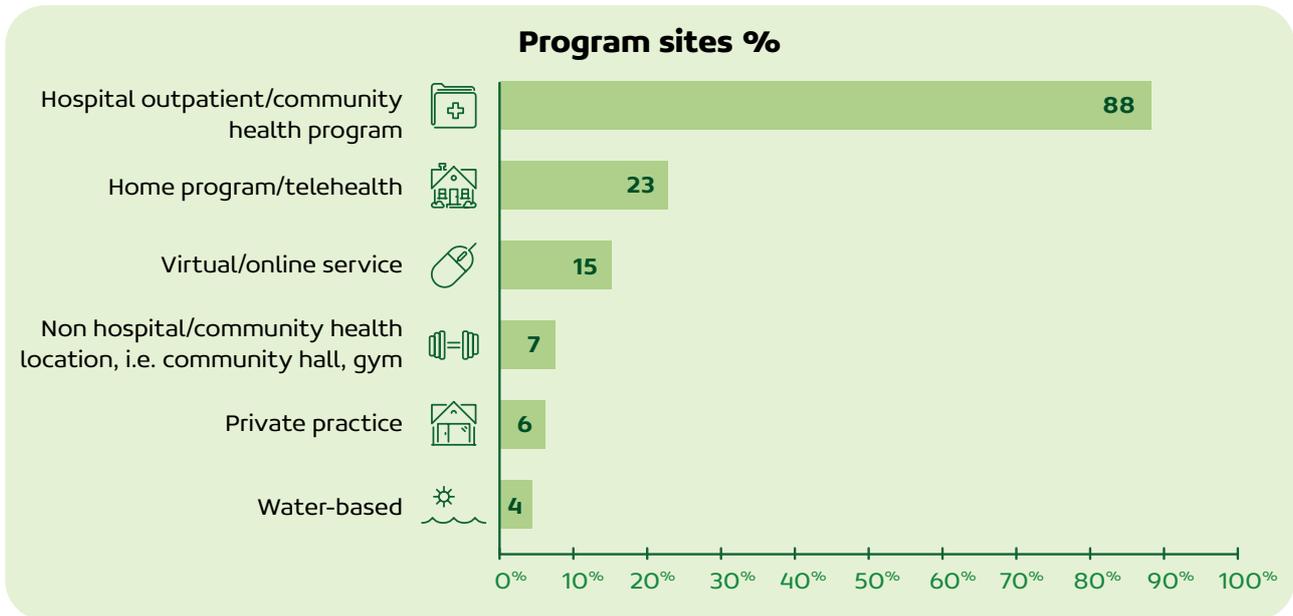
Referrals accepted from

(Services selected all options that applied)



Fig 7: 2022 National Audit of Pulmonary Rehabilitation - Lung Foundation Australia
Referral sources to PR programs

..... **PR program types, sites and staffing**



Type of health professionals involved in programs

(Services selected all options that applied)

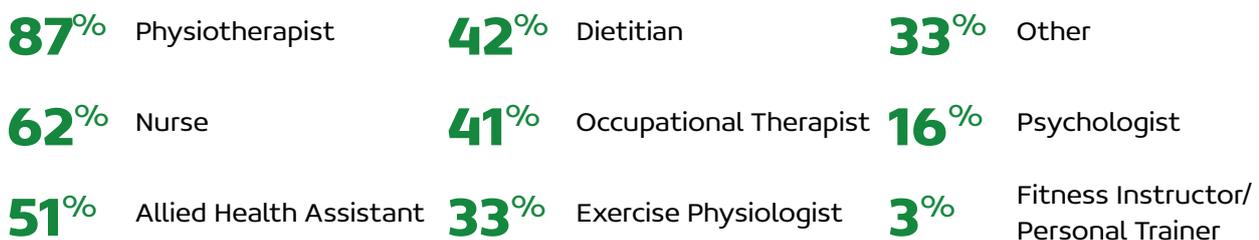


Fig 8: 2022 National Audit of Pulmonary Rehabilitation - Lung Foundation Australia
PR program types, sites and staffing

Consumer engagement

As part of the 2023 PR strategy project, feedback was gathered from consumers regarding their thoughts and experiences about PR using a survey on Lung Foundation Australia social media channels (Instagram and Facebook). The survey ran in June 2023 and received a total of 66 responses, with 43% of respondents from a metro area and 57% from a regional/remote/rural location. There were 12 questions, two of which were exclusive for consumers who had not attended a PR program and seven for consumers who had attended (Appendix 3).



Highlights:

The survey validated the key action areas identified in the November 2022 KOL session and the May 2023 PR Network Symposium, with feedback indicating that poor access to programs and a general lack of awareness of the benefits of PR were the main reasons preventing consumers from attending.



Access and availability:

- 46% of respondents had not attended a PR program. Out of these, 37% could not attend as there was not a program in the local area or they were on a wait list.
- In a free text question asked exclusively to the 46% who had not attended a program, “*What would encourage or support you to attend a PR program?*” 47% of respondent’s comments indicated that access to a local service would encourage them to attend.



Image and awareness:

- Of the 46% of respondents who had not attended a program, 29% confirmed it was because they had never heard of PR and 3% did not think it would help them.
- In a free text question asked exclusively to the 46% who had not attended a program, “*What would encourage or support you to attend a PR program?*” 12% of respondents commented that they would need more information about what it is; “*Knowing it’s ideal for my condition*”, “*Knowledge that such a thing existed in the first place*”.
- Feedback provided within the general comments section at the end of the survey showed that 18% would like more information about what PR is and how it can help them. “*I have stage 1 lung cancer, is this for me?*”, “*I am not sure how I would benefit from it.*”



Economics:

- 12% of respondents commented that they would be more likely to attend a program if funding were available; “*NDIS funding*”, “*Being free*”, “*People in rural areas are often overlooked when it comes to medical services. It is VERY expensive to travel and stay in accommodation in the city and it is physically exhausting.*”

Pathway of care

The PR pathway of care demonstrates the significant role that PR plays as part of the care continuum for people living with a lung condition. People with an eligible lung condition should be referred to PR, complete a 6-8 week program, be referred to a maintenance program and feel supported to become more confident and capable of continuing self-management at home or within their community. Patients can be referred back into PR if they experience a flare-up or increased breathlessness during exercise.

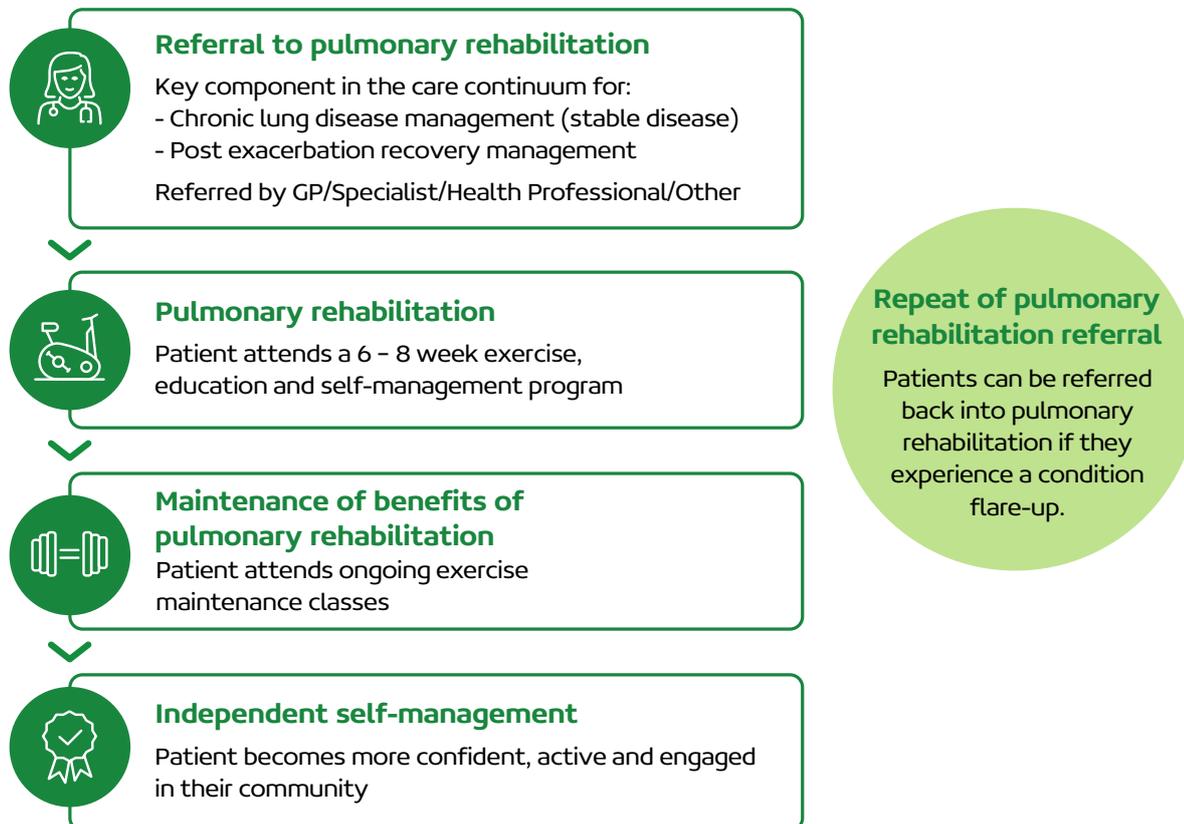


Fig 9: PR pathway of care

The economic cost-benefit of PR

Hospital care for lung conditions presents an enormous cost to the Australian health system. The Australian Institute of Health and Welfare (AIHW) estimates an annual expenditure of \$994.8 million for COPD with \$615.1 million being for hospital services. The average cost for a hospital admission due to COPD exacerbation is \$9,700 in metro areas and \$12,000 in regional hospitals (AIHW 2023). In Australia in 2018, COPD was the leading cause of potentially preventable hospitalisations, which are hospitalisations that may have been prevented by provision of

evidenced-based interventions delivered in primary care (AIHW 2020).

There is strong evidence that participation in PR reduces hospital admissions and length of stay (Jenkins et al. 2024 & Walsh et al. 2019). A recent systematic review (Jenkins et al. 2024) showed that attending PR after a hospital admission reduced hospital readmissions by 52%. An Australian study demonstrated cost savings of \$10,620 per patient per year for those who completed PR compared to those who did not (Burge et al. 2020).

Economic cost-benefit of PR



Remote and very remote areas had 2.1 x more COPD deaths per population when compared with major cities



\$615.1 million

annual health system cost for COPD hospital admissions



\$9,700

average cost for COPD hospital admission in metro areas



\$12,000

average cost for COPD hospital admission in regional remote locations



The cost reduction for each PR completer - average

\$10,620

per year (Burge 2020).

Fig 10: Health system costs of chronic lung conditions and benefit of completing PR

With increased funding for provision of PR in primary care, consumers with COPD or ILD would be able to access PR locally. This change would mean that PR programs would be more accessible to these consumer groups as programs would be closer to their homes and, importantly, more available to those living in rural or remote areas. Funding for PR in primary care would also improve access for Aboriginal and Torres Strait Islander Peoples who could attend PR through programs provided by physiotherapists or accredited exercise physiologists and Aboriginal Health Workers in Aboriginal Community Controlled Health Services (ACCHS) (Meharg et al. 2023).

The proven health outcomes achieved through PR for those with COPD, ILD and bronchiectasis are improved exercise capacity and health-related quality of life (McCarthy et al. 2015

(COPD); Dowman 2021 (ILD); Lee et al. 2021 (bronchiectasis), reduction in symptoms of dyspnoea and fatigue (McCarthy et al. 2015 (COPD); Dowman 2021 (ILD); Lee et al. 2021 (bronchiectasis), and for COPD specifically, reductions in hospitalisations and length of stay (AIHW 2023; AIHW 2020; Walsh et al. 2019) and reductions in hospital re-admissions after an exacerbation (Jenkins et al. 2024). Exercise training may also improve or avoid the decline in exercise capacity, improve health-related quality of life and reduce symptoms of dyspnoea for adults with lung cancer (Cavalheri et al. 2019; Peddle-McIntyre et al. 2019).

These factors are not only important for the consumer but have considerable cost-benefits for the economy and health system.

PR Strategy Framework

The following section provides an overview of the PR Strategy Framework, outlining the key areas in which harmonised and coordinated national action is required. This Framework focuses on building awareness of the benefits of PR and on establishing and documenting the compelling case for change in the provision and funding of services so that they are available and accessible for all who could benefit from quality PR programs no matter their location, circumstance, lung condition, cultural and language aspects or choice of mode of delivery.

Central to the PR Strategy Framework is improving health and wellbeing for consumers through access, referral and completion of PR.



Improve health outcomes through access, referral and completion of PR

This is to be achieved by taking cumulative action in all four key areas, each comprising a range of themes and within these, defined activities which together will deliver the desired outcomes.



Image and awareness



Data and service quality



Access



Funding

Achieving the desired outcomes requires a driving force of dedicated, coordinated, engaged, supported and knowledgeable consumers, health professionals, researchers, professional bodies, health organisations and governments working together and taking up the challenge to change the lives of those living with chronic lung conditions for the better through PR.

As the national organisation and peak body representing Australians living with lung conditions, Lung Foundation Australia will champion the PR Strategy Framework, engaging, consulting and collaborating across the sector to achieve the targets defined in each key area. We will also provide guidance for governments, jurisdictions and individuals in implementing local activities which align to the key recommendation areas and desired outcomes. The success of this work relies on strong partnerships with dedicated consumers, clinicians, policy makers and funders who see this framework as a blueprint for change and an opportunity to collaborate and focus on implementing key initiatives that will deliver better outcomes.

Lung Foundation Australia will actively monitor and evaluate progress in all areas of the Framework and will report periodically to Government and implementation partners. Where feasible, reporting will consider the broad health policy environment and achievement of outcomes also aligning other key policies and strategies as identified in the aforementioned section *The 2023-2026 National Pulmonary Rehabilitation Strategy Framework Project* (pg. 11).

The PR strategy framework

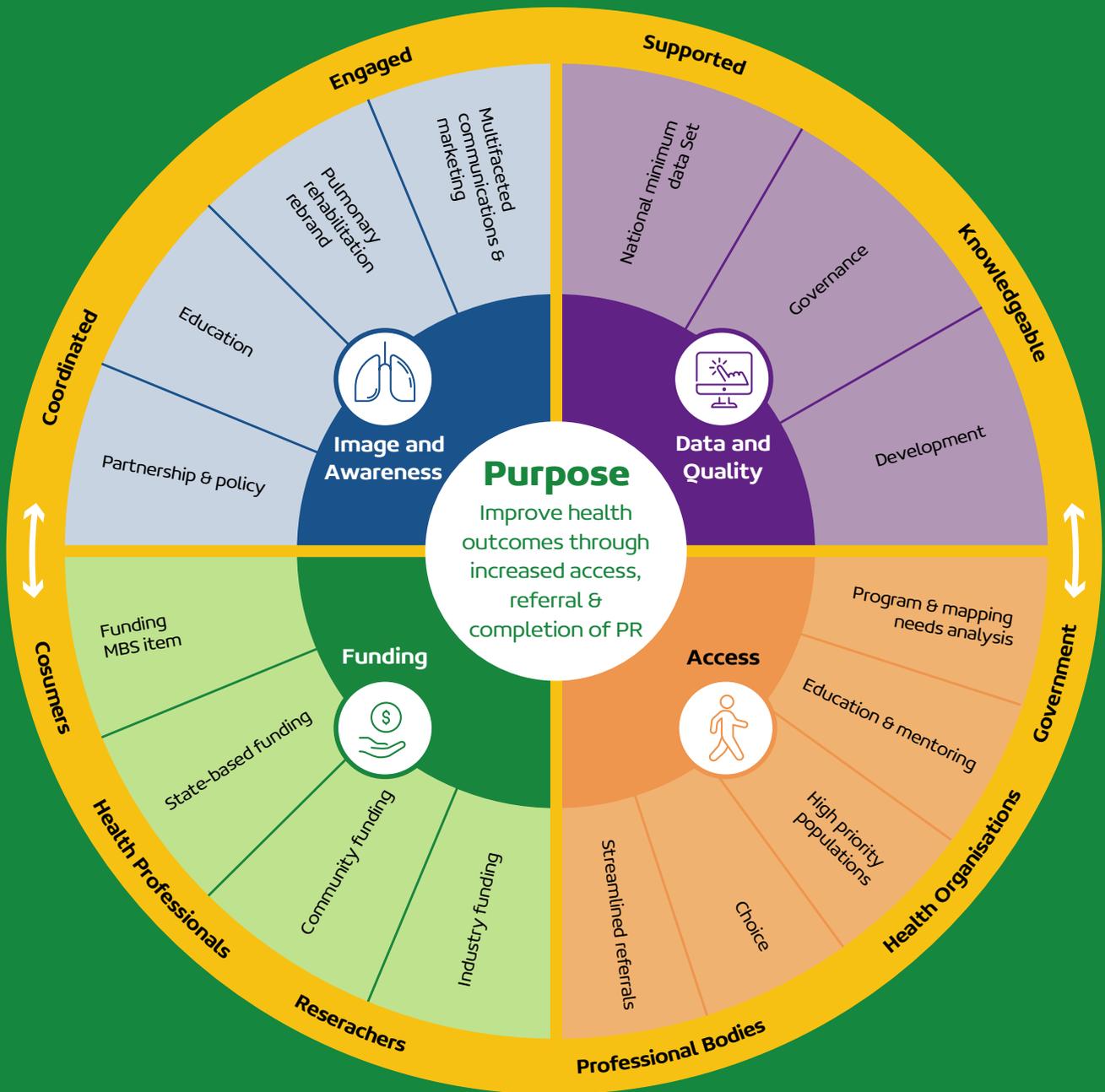
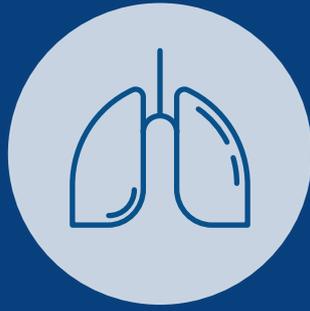


Fig 11: PR strategy framework



Key action area 1

Image and awareness



“People think you have to have had a serious life-threatening event to be doing rehabilitation. They don’t understand all the wonderful positive advantages of PR.”

- Sharon, Melbourne VIC

Evidence of the benefits of PR for those with lung conditions to live and breathe better is clear. However, there are low levels of awareness and understanding amongst consumers, healthcare professionals and decision-makers of the existence, relevance and positive outcomes of participation and completion of quality PR programs. There are also misconceptions about what PR is, when patients should be referred and who it is suitable for. This requires clarification.

Goal

The goal of the **Image and awareness key action area** is three-fold:

1. For consumers to understand what PR is and how it will help them manage their condition and improve quality of life at different points in their lung health journey
2. For health professionals to be aware of the benefits of PR and understand how to refer consumers into a program
3. For decision makers to understand and consider the benefits of PR and the health, social and financial benefits of investing in it.

Theme 1: Multi-faceted communications and marketing

Approach to reach consumers, health professionals and decision makers to increase knowledge and understanding, dispel misinformation and to increase availability of and participation in PR.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none"> Awareness campaign to promote what PR is, the benefits and its efficacy 	<ul style="list-style-type: none"> Development and implementation of a marketing and communications strategy with multi-tactic, multi-channel activities delivering key messages 	<ul style="list-style-type: none"> Increased awareness of PR and its benefits
<ul style="list-style-type: none"> Recruit PR champions from amongst consumers, clinicians and providers 	<ul style="list-style-type: none"> Panel of champions briefed and confident to promote PR 	<ul style="list-style-type: none"> Greater knowledge about and confidence in the efficacy of PR
<ul style="list-style-type: none"> Consumers with a range of respiratory conditions, showcase the benefits of PR to them 	<ul style="list-style-type: none"> Repository of stories in range of formats An active group of consumers willing to talk about PR 	<ul style="list-style-type: none"> Positive attitudes towards PR as key to managing a range of lung conditions
<ul style="list-style-type: none"> Clinicians supportive of PR showcase its value 	<ul style="list-style-type: none"> Growing list of active clinicians from a range of disciplines 	<ul style="list-style-type: none"> Increase in clinicians referring to PR
<ul style="list-style-type: none"> Infographics on the benefits of PR across the lung condition spectrum and stages together with consumer journey mapping 	<ul style="list-style-type: none"> Visuals are easily understood by consumers and health professionals and are being used 	<ul style="list-style-type: none"> Clearer understanding of where PR fits in management of chronic lung conditions
<ul style="list-style-type: none"> Service mapping (lung maps) <ul style="list-style-type: none"> Produce a national 'living' map of where people with lung conditions live, and where PR programs are to illustrate service availability, gaps and needs 	<ul style="list-style-type: none"> Completion of the map 	<ul style="list-style-type: none"> Clarity on the situation and providing a baseline on what to build

Theme 2: PR rebrand

Targeting consumers to focus on a more positive, health- and future-focused brand and image appropriate for all people with a lung condition.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none"> Reposition the image of PR through a co-designed approach with consumers and health professionals 	<ul style="list-style-type: none"> Increased positive attitudes towards PR Increased referrals by health professionals Positive, future-focused and relevant information is accurately conveyed 	<ul style="list-style-type: none"> Better understanding and positive attitude toward PR Branding is clear about who the programs are for and what they involve
<ul style="list-style-type: none"> Reframe PR with the addition of the term that resonates with, and is better understood, by consumers living well with a lung condition 	<ul style="list-style-type: none"> Participants and potential participants are positive towards and clear about the relevance of PR to them People living with lung conditions regard PR as positive and beneficial 'New' name is being used in promotional materials and by consumers and health professionals 	<ul style="list-style-type: none"> A name that is meaningful and welcoming to participants

Theme 3: Education

Working across a range of settings and career stages to educate current and future clinicians about PR and incorporating peer and consumer-led ways of working.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none"> Develop a comprehensive health professional education strategy incorporating peer-led approaches that will reach: <ul style="list-style-type: none"> Hospital-based staff Specialists General practitioners Allied health professionals Undergraduates and new graduates Private and public settings 	<ul style="list-style-type: none"> Incorporation of PR in CPD opportunities Hospitals providing PD opportunities - incidental and planned Undergraduate courses including PR as part of lung conditions curriculum 	<ul style="list-style-type: none"> Knowledge re PR across the spectrum of health professionals Increased referrals to PR

Theme 4: Partnerships and Policy

Raising the profile of PR and getting it on the agenda of decision makers at a State, Territory and national level requires joint activity involving partnering with organisations that share an interest in lung health and key aspects of PR.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none">Develop a 'case' for increased action around PR that helps to build an alliance with key health peak and membership bodies, particularly those seen as 'go to' organisations for information and advice. Provides a call to action for state and territory governments	<ul style="list-style-type: none">Policy makers at federal and state / territory level are aware of PR benefit and the cost benefit of referring people to PR e.g., decreased hospital admissions	<ul style="list-style-type: none">Increased support and funding to improve access and availability of PR no matter of location or circumstances

Sharon's story

Sharon McInerney was diagnosed with bronchiectasis in her early 50's. She had tried a number of exercise classes in her local area but had struggled to keep up with them.

"It is very energy sapping when you are not well. The negativity of being the chronic unwell person creeps in."

Her GP had never referred her to pulmonary rehabilitation as they were not aware it existed. It wasn't until her early 60s, after a series of repeat chest infections, that a lung specialist put her in touch with a team at her local hospital who offered her the opportunity to join a home-based PR program.

"I was just thrilled! It really did change my lungs and it educated me. It was good to be in a class with others who were similar to me."

Sharon found the online format to be a lot easier than having to travel to her local hospital twice a week which would have taken up half a day. The program taught her to be positive and not fearful of exercising with her condition. It gave her the knowledge and strategies of how to pace herself, so she was able to keep active.

"What PR taught me was to not be fearful but be positive. When you are not well you allow yourself to be fearful and not take the hill. Through PR you learn how to pace yourself and stop and rest and take the hill!!"

Exercise now forms a part of Sharon's daily routine. She goes out for daily walks and feels the difference if she is unable to go. She has educated her local GP about PR and reminds them to refer other patients with a lung condition into their local PR service.



Key action area 2

Data and service quality

Currently there is a lack of Australian data on the outcomes and impacts of PR programs giving rise for the need for a strong, consistently collected data set that will enable benchmarking for understanding and reducing variations in care to ensure quality service provision and continuous quality improvement.

While data is being collected, it is being done in a fragmented fashion. There is an absence of an agreed national minimum data set and while some states, territories and health bodies have designed and implemented systems that capture valuable PR information, to date there is not a nationwide agreement on what this should encompass.

The ability to benchmark and to gather and monitor data in real time will lead to effective models of delivery and improved consumer outcomes nationwide.

Aligned with the development of a minimum data set is to conduct an audit of PR programs across Australia which will provide a snapshot of current activity.

Goal

Establish national standard outcome measures for PR. Develop real-time data gathering systems to evaluate outcomes of PR programs against national standards.

Theme 1: National minimum data set

To determine a national minimum data set incorporating minimum clinical standards of practice, and consumer outcomes, which includes a repository and audit mechanism with appropriate governance and standards.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none"> Determine the requirements of national data collection of service information, consumer outcome measures and clinical standards 	<ul style="list-style-type: none"> Criteria established for minimum data set contributed to by relevant stakeholders 	<ul style="list-style-type: none"> National benchmarking, monitoring and continuous improvement of services and clinical outcomes
<ul style="list-style-type: none"> Build the business case defining why a national minimum data set needs to be funded and the benefits 	<ul style="list-style-type: none"> A comprehensive business case ready for presentation to funders and decision makers 	<ul style="list-style-type: none"> Funded platform and organised support
<ul style="list-style-type: none"> Explore the potential for building on / extending current models 	<ul style="list-style-type: none"> Report and recommendations 	<ul style="list-style-type: none"> Harmonised and consistent platform enabling data collection and analysis
<ul style="list-style-type: none"> Conduct a national audit of current PR 	<ul style="list-style-type: none"> Audit conducted 	<ul style="list-style-type: none"> Accurate picture of where PR is being delivered, how, to whom, by whom etc and what the outcomes are A consistent standard of service regardless of location

Theme 2: Development of minimum data set

For a minimum data set with a repository and audit function to be established and operated successfully it requires support and a willingness to participate, contribute and to promote outcomes.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none">Undertake information / education sessions to address any concerns / questions relating to value of a minimum data set, ethics relating to data sharing, time needed for data entry and any cross-jurisdiction issues	<ul style="list-style-type: none">Clinicians, state health departments know about, see the value of and support the establishment of a minimum data set	<ul style="list-style-type: none">Nationally harmonised approach to collecting data and reporting on PR

Theme 3: Governance

The data collection tool needs to be governed by a provider with experience in managing national clinical quality registries and managing conflict of interest.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none">Consultation with key stakeholders from the KOL group to determine which organisation would be best positioned to take ownership of the data collection. Sustainability, conflict of interest, quality and creditability of the output needs to be taken into consideration	<ul style="list-style-type: none">An agreement of who would be best placed to own the data collection tool that will result in a high quality, sustainable national registry	<ul style="list-style-type: none">A funded platform governed by an experienced organisation

Queensland (QLD) data collection – A success story

COPD and asthma account for over 5% of the total burden of disease in Queensland.

Dr James Walsh is a physiotherapist working in QLD Australia. As a member of QLD Health's Respiratory (& Sleep) Clinical network, James takes an active role in the promotion and development of PR across the state.

With the arrival of COVID-19 in 2020, James had raised his concerns of the importance of developing some sort of workaround for PR to continue throughout the pandemic. Through his connections in the clinical network, PR was prioritised within Clinical Excellence Queensland, and funding was obtained to commence a project to develop, implement and evaluate strategies to increase the capacity within QLD PR programs to support the equitable access for chronic respiratory patients.

The funding allowed for project managers, Rebecca Chambers and then Nadia Nestor, to drive the process and develop good relationships with the QLD PR programs, which contributed significantly to the success of the project.

The project commenced in October 2020 and included the roll out of:

1. An evidence-based telerehabilitation framework that supported and streamlined service provision and informed the ongoing delivery of quality virtual models of PR.
2. A co-ordinated approach towards updated data reporting and systems including the digital integration of Measuring Analysis and Reporting System (MARS) data collection with a power BI benchmarking platform and QHERS automated reporting system.

3. Advocacy and support for PR service providers and programs within the state-wide PR working group network.

The project delivered some significant outcomes across the state.

Phase one (October 2020 to June 2021) outcomes included the development of a virtual rehab framework and a state-wide PR data collection. The implementation of a telerehab service reduced travel by 8,704km and 114 hours, and travel-related cost saving of over \$6,266 for the initial four trial site participants.

Phase two (July 2021 to June 2022) outcomes included the development of a clinical implementation guide, 14/19 QLD programs transitioned to virtual PR, an update to the state-wide PR data collection (MARS) and the development of endorsed quality indicators with a real time power BI dashboard.

Data was collected using MARS which is an excel-based form. The form has five pages and took under eight minutes to complete. An automated completion letter was generated within 24 hours of submission of the data. The responses from this fed into a state-wide PR dashboard which summarises outcomes from all services.

Phase three (July 2022 and onwards) the data collected as part of the initiative, will support further funding opportunities to address equity of access within regional and remote programs as well as refinements to the quality of data input.



Key action area 3

Access



“People in rural areas are often overlooked when it comes to medical services. It is VERY expensive to travel and stay in accommodation in the city and it is physically exhausting.”

- Consumer

Despite the clear clinical benefits of PR, access in Australia is extremely limited with estimations of fewer than 10% of people who would benefit from PR having access to it.

Consumers don't always take up the offer of PR for a range of reasons, even when they are referred. While most of PR programs operate in hospital settings, many consumers with lung conditions are managed by their GP in their communities, where they may have no access to a PR program that could deliver real benefit. Availability of community and home-based programs would improve access considerably.

Goal

For all consumers to have access to high-quality PR programs regardless of their location and ethnicity.

The COVID pandemic disrupted delivery of PR with many services forced to close down or operate online due to the vulnerability of participants. Many of these PR programs have not as yet been re-established, some have long waiting lists or struggle to work with the increased complexity of their participant's lung conditions.

Important to improving access to programs is the recognition of, and tailoring services to, Aboriginal and Torres Strait Islander Peoples and other high-priority populations who, because of culture, language, location, economics, or circumstance, do not have access and the opportunity to access quality, culturally safe PR programs.

Since the COVID-19 pandemic, new health concerns have risen for many Australians who are experiencing post-acute symptoms, such as breathlessness (Lung Foundation Australia 2022). Long COVID may cause a spectrum of symptoms, including fatigue, myalgia, palpitations, muscle or joint pain, chest pain or tightness, dyspnoea at rest or on exertion, sleep difficulties, loss of smell and taste, gastrointestinal complaints (diarrhoea, nausea), headache, and hair loss (Sengupta & Jenkins 2022).

Through exercise and self-management education, PR may be effective in supporting people with ongoing COVID-19 symptoms and COVID-19 recovery. A PR audit completed by Lung Foundation Australia in September 2022 identified that 59% of PR programs were supporting patients with long COVID, with referrals primarily originating from long COVID clinics. Additional places in PR programs need to be funded, to enable increased capacity to provide rehabilitation for people with continued respiratory symptoms after COVID-19 infection and to ensure equitable support for Australians regardless of their location and financial position.

Theme 1: Streamlined referrals

An integrated referral system is available and accessible to all clinicians.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none"> • Improve (simplify) and standardise referral pathways • Development of technology platforms to support referral pathways for primary care and acute services • Development of clinician support tools 	<ul style="list-style-type: none"> • Evidence of visible and easily accessible referral pathways • Improved and standardised referral tools and processes that GPs can use 	<ul style="list-style-type: none"> • Increased referrals across a range of locations and for a range of conditions at an earlier stage

Theme 2: Choice

To optimise the opportunity for people with lung conditions to participate in PR programs, there needs to be choices available that account for individual preferences.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none"> • Develop and implement a range of evidence-based PR models in response to consumer needs and preferences: <ul style="list-style-type: none"> – including affordability – across all lung conditions 	<ul style="list-style-type: none"> • Hospital, community, home/online models available, evaluated and utilised 	<ul style="list-style-type: none"> • Greater range of people with lung conditions able to choose the delivery model best suited to their situation
<ul style="list-style-type: none"> • Facilitate development of and access to an approved mHealth PR solution 	<ul style="list-style-type: none"> • An approved consumer-facing app in the marketplace 	<ul style="list-style-type: none"> • Ability to reach and engage with greater proportion of people living with lung conditions

Theme 3: High priority populations

Comprehensive consultation with Aboriginal and Torres Strait Islander Peoples and other high priority populations is required to ensure tailored, culturally safe and appropriate services are available and accessible.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none"> Work with consumers and relevant health organisations to investigate approaches and models of PR shown to have positive outcomes for Aboriginal and Torres Strait Islander Peoples and other high priority populations 	<ul style="list-style-type: none"> Engagement of those most affected in documenting evidence around successful approaches 	<ul style="list-style-type: none"> More and better suited, culturally safe PR programs accessible to all who require them
<ul style="list-style-type: none"> Support co-designed action research to develop culturally safe and relevant approaches for PR 	<ul style="list-style-type: none"> Funded research projects 	<ul style="list-style-type: none"> High levels of participation in appropriate and accessible PR programs
<ul style="list-style-type: none"> Promote and promulgate approaches and models demonstrated to be effective 	<ul style="list-style-type: none"> Publication of research findings Guidelines include recommendations for a range of effective models Evidence of more and greater range of programs 	<ul style="list-style-type: none"> Greater availability of PR programs in a range of modes and settings Higher completion rates
<ul style="list-style-type: none"> Ensure that cost and distance are not barriers to participation 	<ul style="list-style-type: none"> Consumer feedback on ability to participate 	<ul style="list-style-type: none"> More people able to participate and complete programs

Theme 4: Education and mentoring

For health professionals across tertiary, secondary and primary care settings to understand the benefits of PR. There are existing guidelines which need to be followed to ensure quality and consistency of care. Education, support and mentoring for health professionals is an important aspect to increase timely referrals to PR and to provide a quality, accessible service.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none"> Develop new and promote existing health professional education, training and resources to: <ul style="list-style-type: none"> Undergraduates and degree level training in curriculum General Practitioners and General Practice Staff Hospital-based clinicians and nursing staff Physiotherapists and accredited exercise physiologists 	<ul style="list-style-type: none"> Evidence of information about PR in professional publications and courses Participation in training and education offerings 	<ul style="list-style-type: none"> More health professionals knowledgeable about, and confident to refer or conduct PR programs
<ul style="list-style-type: none"> Provide mentoring opportunities to health professionals through: <ul style="list-style-type: none"> PR Network Workplace app Visits between PR programs arranged through PR Network 	<ul style="list-style-type: none"> Monitoring of use of PR Network app for informal and more formal mentoring Participation in visiting program 	<ul style="list-style-type: none"> Stronger and more supportive professional networks Higher quality PR offerings

Theme 5: Program mapping and needs analysis

Clearer understanding of where areas of high need are and the particular needs of consumers and health professionals to ensure this is available and accessible to all who could benefit.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none"> Undertake a comprehensive mapping exercise of lung conditions in Australia including health, economic, social, cultural factors: <ul style="list-style-type: none"> include where PR Network members are located 	<ul style="list-style-type: none"> Better planning and responses through creation of a 'Lung map' of Australia that provides a picture of local needs and availability of PR and other services enabling provision of extra resources in high needs areas Participation in the gathering of data to build a 'Lung map' of Australia A completed, useful and usable mapping exercise including needs analysis 	<ul style="list-style-type: none"> Services provided where, when and how they are needed



Key action area 4

Funding mechanisms



“Proximity and cost are the main barriers stopping me from attending a program.”

- Consumer

The economic aspect of PR is multifaceted and needs to be tackled at several levels. For consumers the cost of PR can be a barrier to participation and associated costs such as travel and time off work to access programs add to the burden. Funding of community-based sessions close to home is limited for most people living with lung conditions.

Providers often have difficulty building a financially viable business model that supports ready access to those who would benefit from PR. Medicare subsidised MBS item numbers for primary care-based exercise programs would



Goal

Increased funding for PR through local and government initiatives.

support increased access and equity, and primary care funding, incentivising referrals would drive increased participation.

Funding within the hospital setting can be varied and complex with tier two funding being used in a range of ways. Using this funding stream to support PR programs could make a positive difference.

Community, state / territory and federal financial investment is key to optimising the potential benefit of PR programs.

Theme 1: Federal funding

MBS items for primary care-based exercise programs are required to increase referrals and to support access and improve equity for consumers.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none">• Introduction of an MBS item and appropriate re-imburement for the completion of an eight-week program of PR provided in primary care	<ul style="list-style-type: none">• Positive MSAC recommendation	<ul style="list-style-type: none">• Increase in referrals to PR programs• Increased participation in and completion of base PR program

Theme 2: State-based funding

State and territory governments have a key role in supporting PR. They are responsible for public hospitals, public health and community services and are supported through state taxes together with Commonwealth funding. Some states are already demonstrating how to develop a system-wide approach to PR.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none">• Build evidence of PR program impact and continuing unmet need together with business case for financial investment	<ul style="list-style-type: none">• State and territory investment in PR	<ul style="list-style-type: none">• Availability of PR for all who could benefit

Theme 3: Community and industry funding

In addition to federal, state and territory funding sources there are additional potential funding mechanisms including local government through community-based care. In the private sector, the private health insurance industry is developing a role in primary healthcare through allied health care and preventive and chronic disease self-management programs.

Activity	Success / Measure	Outcome
<ul style="list-style-type: none">• Promote PR to local government and community agencies as an important component of community-based care	<ul style="list-style-type: none">• Availability of PR programs at a local level	<ul style="list-style-type: none">• Those living with a lung condition able to access PR locally
<ul style="list-style-type: none">• Demonstrate the effectiveness of PR as an additional and potentially cost saving benefit to private health insurance providers	<ul style="list-style-type: none">• PR available as a benefit to private health insurance holders• Evidence of benefit feeds into national data collection	<ul style="list-style-type: none">• Ready access for those with private health insurance• More data to support universal funding

Summary of recommendations

The burdens of chronic lung conditions in Australia are widely acknowledged and the benefits of PR for consumers, communities and health systems are clear, yet equity and access to best-practice services continues to be extremely limited, especially in regional, rural and remote communities and for CALD and Aboriginal and Torres Strait Islander Peoples.

Lung Foundation Australia believe that all Australians should be empowered with the opportunity to proactively manage their lung condition regardless of their geographical location, culture, language or socio-economic status.

In consultation with a national network of KOLs in PR, four key action areas have been identified in the PR Strategy Framework that together, will improve awareness and increase access and equity of PR for all Australians. Through implementation and uptake of the Framework and its recommendations we aspire to reduce potentially preventable hospital admissions, improve quality of life, and increase active societal participation of those living with lung conditions.



Image and awareness

There needs to be an increased awareness and understanding of PR achieved through:

A multi-faceted communications and marketing approach to reach consumers, health professionals and decision makers to increase knowledge and understanding, dispel misinformation and to increase availability of and participation in PR.

A PR rebrand - targeting consumers to focus on a more positive, health and future-focused brand and image appropriate for all people with a lung condition.

Education - working across a range of settings and career stages to educate current and future clinicians about PR and incorporating peer and consumer-led ways of working.

Partnerships and policy - raising the profile of PR and getting PR on the agenda of decision makers at a state, territory and national level requires joint activity involving partnering with organisations that share an interest in lung health and key aspects of PR.



Data and service quality

A national quality data collection tool is needed to increase understanding of the consumer outcomes of PR and ensure equity of service provision.

A national minimum data set - determination of a national minimum data set incorporating minimum clinical standards of practice and consumer outcomes including a repository and audit mechanism with appropriate governance and standards.

Development of minimum data set - for a minimum data set with a repository and audit function to be established and operated successfully, it requires support and a willingness to participate, contribute and to promote outcomes.

Governance - the data collection tool needs to be governed by a provider with experience in managing national clinical quality registries and managing conflict of interest.



Access

All Australians should have access to a PR service regardless of their geographical location, culture and language and socio-economic status.

A streamlined referral process - an integrated referral system is available and accessible to all clinicians.

Choice - to optimise the opportunity for people with lung conditions to participate in PR there needs to be choices available that account for individual preferences.

High priority populations - comprehensive consultation with Aboriginal and Torres Strait Islander Peoples and other high priority populations is required to ensure tailored, culturally safe and appropriate services are available and accessible.

Education and mentoring - that health professionals across tertiary, secondary and primary care understand the benefits of PR. There are existing guidelines which need to be followed to ensure quality and consistency of care. Education, support and mentoring for health professionals is an important aspect to increase timely referrals to PR and to provide a quality, accessible service.

Program mapping and needs analysis - PR currently is not available or accessible to all who could benefit from it. It is important to have a clearer understanding of where areas of high need are and the particular needs of consumers and health professionals.



Funding mechanisms

Cost should not be a barrier to attendance.

Federal funding - MBS item for primary care-based PR programs is required to increase referrals and to support access and improve equity for consumers.

State-based funding - state and territory governments have a key role in supporting PR. They are responsible for public hospitals, public health and community services, which are supported through state taxes together with Commonwealth funding. Some states are already demonstrating how to develop a system-wide approach to PR.

Community and industry funding - In addition to federal, state and territory funding sources there are other potential funding mechanisms including local government through community-based care. In the private sector, the private health insurance industry is developing a role in primary health care through allied health care and preventive and chronic disease self-management programs.



“I know participating in the pulmonary rehabilitation program certainly was a great benefit to myself and others in my group. Ten months post-transplant I still implement some of which I learnt. Totally recommend everyone to complete the program.”

“It was fantastic and gave me fitness and confidence as well as creating motivation for me to get fitter.”

“It’s not only about rehabilitation it’s also about preventative measures/exercises and fitness especially when you don’t know how far you should push yourself and possibly make things worse.”

Consumer testimonials

Glossary of terms

ACSQHC	Australian Commission on Safety and Quality in Healthcare
AIHW	Australian Institute of Health and Welfare
CALD	Culturally and Linguistically Diverse
Comorbidities	More than one condition
COPD	Chronic Obstructive Pulmonary Disease
COPD Blueprint	A Lung Foundation Australia publication highlighting the seriousness of COPD, outlining the action that needs to be taken
COPD-X Guidelines	Australian and New Zealand Guidelines
Exacerbations	An acute increase in the severity of the problem
GP	General Practitioner
Home-based PR	An alternative rehabilitation model completed within a consumer's home.
KOL	Key Opinion Leader Group
MBS	Medicare Benefits Schedule
MSAC	Medical Services Advisory Committee
NDIS	National Disability Insurance Scheme
PR	Pulmonary Rehabilitation
PR Network	Pulmonary Rehabilitation Network - A network governed by Lung Foundation Australia for health professionals and academics working in PR

Appendix one:

Acknowledgements

Lung Foundation Australia representatives

Mr Mark Brooke	Chief Executive Officer, Lung Foundation Australia
Prof Jennifer Alison	PR Network Chair, Professor of Respiratory Physiotherapy, University of Sydney
Ms Emma Halloran	Pulmonary Exercise Manager, Lung Foundation Australia (2021-2023)
Ms Hailey Fisher	Pulmonary Exercise Manager, Lung Foundation Australia (2023)
Mr Harry Patsamanis	General Manager Consumer Programs and Partnerships, Lung Foundation Australia
Ms Kelcie Herrmann	General Manager Clinical Programs and Research, Lung Foundation Australia
Ms Letisha Hatte	Policy and Project Officer, Lung Foundation Australia
Ms Maree Davidson	Consultant, Davidson Consulting
Ms Paige Preston	General Manager Policy, Advocacy and Prevention, Lung Foundation Australia

Key Opinion Leader Group

Prof Anne Holland	Professor of Physiotherapy, Monash University and Alfred Health
Dr Angela Burge	Research Fellow, Alfred Department of Immunology & Pathology
A/Prof Annemarie Lee	Senior Lecturer, School of Primary and Allied Health Care
A/Prof Catherine Granger	Physiotherapy, The University of Melbourne, Physiotherapy Research Lead, The Royal Melbourne Hospital
A/Prof Christian Osadnik	Director of Research, Department of Physiotherapy, Monash University
Prof Ian Yang	Thoracic Physician & Thoracic Program Medical Director, The Prince Charles Hospital
Dr James Walsh	Physiotherapist, Clinical Consultant; Queensland Lung Transplant Service and Advanced Heart Failure and Cardiac Transplant Unit; The Prince Charles Hospital, Metro North Hospital and Health Service
Prof Jennifer Alison	PR Network Chair, Professor of Respiratory Physiotherapy, University of Sydney
Prof Kylie Hill	Physiotherapy, Curtin School of Allied Health, Curtin University, Perth, Western Australia

Dr Lara Edbrooke	Senior Lecturer, Victorian Cancer Agency Fellow, School of Physiotherapy
A/Prof Lissa Spencer	Clinical Specialist Physiotherapist Pulmonary, Cardiac & Chronic Disease Rehabilitation Royal Prince Alfred Hospital
Ms Mary Roberts	Clinical Nurse Consultant, Respiratory Ambulatory Care Westmead Hospital, Clinical Lecturer, Sydney Medical School, University of Sydney
Ms Nadia Nestor	Accredited Exercise Physiologist and ESSA Representative
Dr Narelle Cox	Senior Research Fellow Alfred Department of Immunology & Pathology
Prof Norm Morris	School of Rehabilitation Sciences, Gold Coast University Hospital
Dr Renae McNamara	Clinical Specialist Physiotherapist, Prince of Wales Hospital
Mr Scott Willis	National President of the Australian Physiotherapy Association
A/Prof Vin Cavalheri	Allied Health Research Director at South Metropolitan Health Service, Faculty of Health Sciences at Curtin University, and Curtin School of Allied Health at Curtin University
A/Prof Zoe McKeough	Sydney School of Health Sciences, Faculty of Medicine and Health

Input and feedback from PR state representatives and PR Symposium Attendees - Not previously listed

Ms Alicia Goodwin	Senior Program Manager COPD, Lung Foundation Australia
Ms Alisa Bursill	New South Wales Health
Dr Andrew Chan	Mobile pulmonary rehabilitation
Ms Caitlin Vicary	Department of Health Western Australia
Ms Christiane Boeham	New South Wales Health
Mr Chris Hall	Tasmanian Health Service
Ms Coralie Brannelly	Northern Territory Health
Mr Daniel Zammit	New South Wales Health
Mr David Meharg	The University of Sydney
Mr David Thompson	Merri Health
Ms Ellen Gibson	Sunshine Coast Hospital and Health Service
Ms Hannah Rutherford	Mobile pulmonary rehabilitation
Dr Hayley Lewthwaite	The University of Newcastle
Ms Helen Seale	Queensland Health

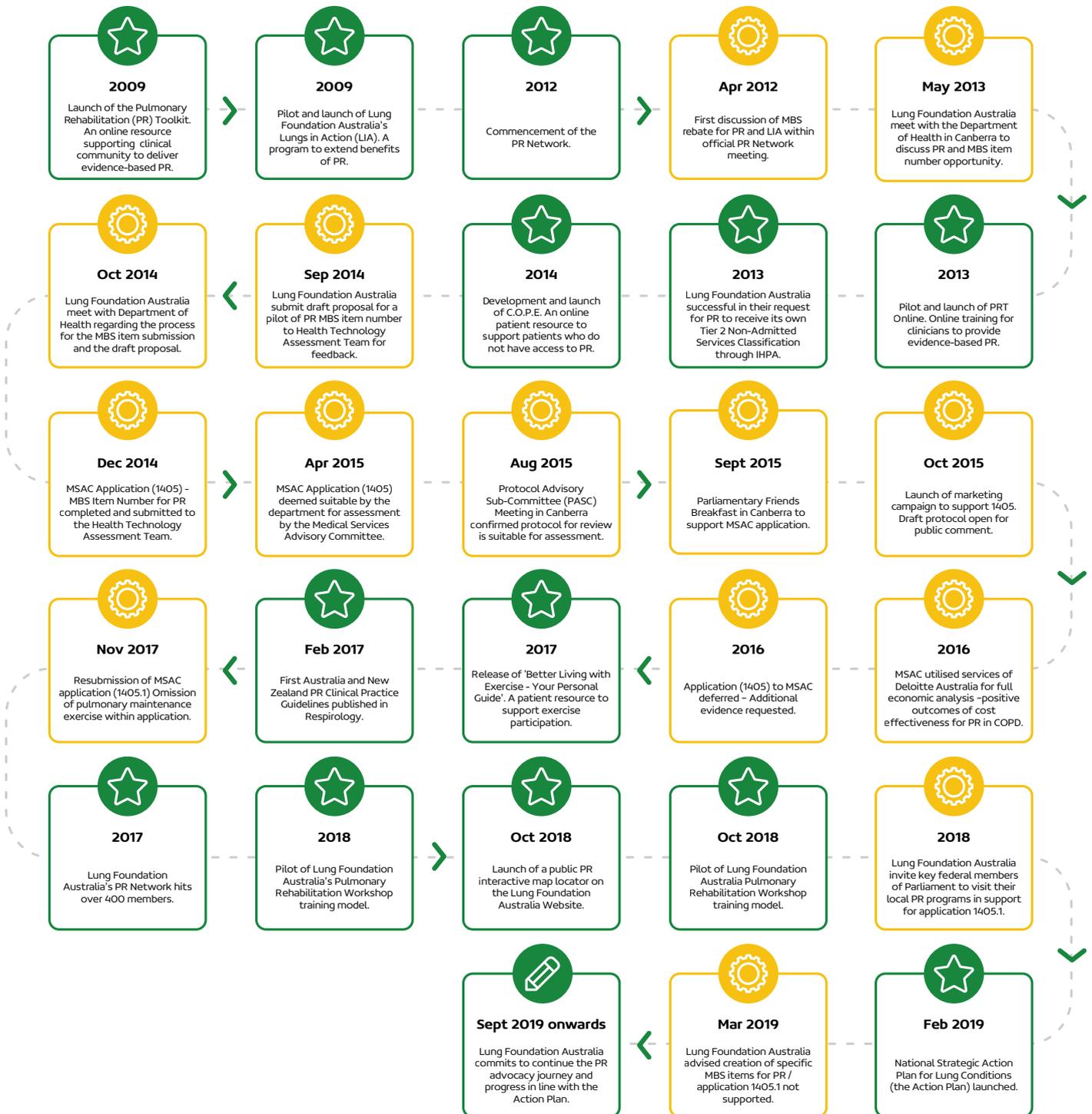
Ms Jane Cotter	New South Wales Health
Ms Janet Bondarenko	Alfred Health
Ms Jeanette Lee	Roche
Ms Jessica Beaman	Tasmanian Health Service
Ms Jessica Walsh	The University of Sydney
Ms Joanna Rivers	South Australia Government
Ms Kristal Grainger	Lungs in Action Community Liaison Coordinator, Lung Foundation Australia
Ms Lili Tang	Queensland Health
Ms Ling-Ling Tsai	The University of Sydney
Ms Liz Havyatt	New South Wales Health
Ms Lorie Wishart	Roche
Ms Lorna Hatcher	New South Wales Health
Ms Marita Dale	The University of Sydney
Ms Melissa Chong	Alfred Health
Ms Naomi Chapman	Department of Health Western Australia
Mr Paul Cafarella	South Australia Government
Ms Robyn Patton	Rural New South Wales
Ms Sahba Dehghani	Peer Support Manager, Lung Foundation Australia
Dr Sally Wootton	Mobile pulmonary rehabilitation

Lung Foundation Australia consumer engagement

Lung Foundation Australia sincerely thank the people living with a chronic lung condition who responded to the online consumer engagement survey, or attended the online consumer feedback session to provide insight into their experiences of PR. These generous contributions ensure that the PR Strategy Framework is first and foremost a resource that responds to consumer lived-experiences and proposes responsive and meaningful solutions.

Appendix two:

Lung Foundation Australia advocacy journey



Appendix three:

Consumer engagement

Overview

As part of the 2023 PR strategy project, Lung Foundation Australia gathered feedback from consumers regarding their thoughts and experiences around PR. Due to a lack of uptake from the Lung Foundation Australia consumer representative group, Lung Foundation Australia published a survey on our social media channels (Instagram and Facebook). The survey received a total of 66 responses, 43% from a metro area and 57% from a regional/remote/rural location. There was a total of 12 questions, two of which were exclusive for consumers who had not attended a PR service and seven for consumers who had attended. This document provides a summary of the results.

Highlights

The survey validated the key action areas identified in the November 2022 KOL session and the May 2023 PR Network Symposium, with feedback indicating that poor access to services and a general lack of awareness of PR being the main reasons preventing consumers from attending.

Access and availability:

- 46% of respondents had not attended a PR program. Out of these, 37% could not attend as there was not a program in the local area or they were on a wait list.
- In a free text question asked exclusively to the 46% who had not attended a program, **“What would encourage or support you to attend a pulmonary rehabilitation program?”** 47% of respondent’s comments indicated that access to a local service would encourage them to attend.

Image and awareness:

- Of the 46% of respondents who had not attended a program, 29% confirmed it was because they had never heard of it and 3% did not think it would help them.
- In a free text question asked exclusively to the 46% who had not attended a program, “What would encourage or support you to attend a pulmonary rehabilitation program?” 12% of respondents commented that they would need more information about what it is; **“Knowing if it ideal for my condition”, “Knowledge that such a thing existed in the first place”**.
- Feedback provided within the general comments section at the end of the survey showed that 18% would like more information about what PR is and how it can help them. **“I have stage 1 lung cancer is this for me?”, “I am not sure how I would benefit from it.”**

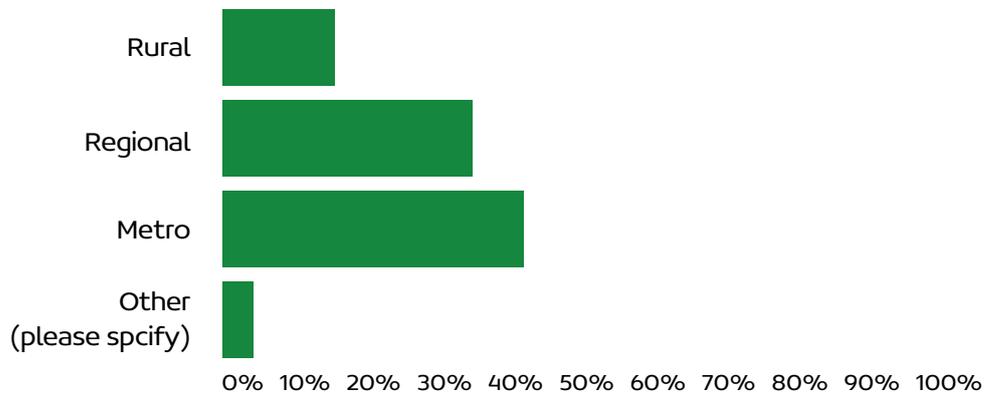
Economics:

- 12% of respondents commented that they would be more likely to attend a program if funding were available; **“NDIS funding”, “Being free and not exercising with other people”, “People in rural areas are often overlooked when it comes to medical services. It is VERY expensive to travel and stay in accommodation in the city and it is physically exhausting.”**

Survey Results

Do you live in a rural, regional or metro location?

Answered: 63 Skipped: 0

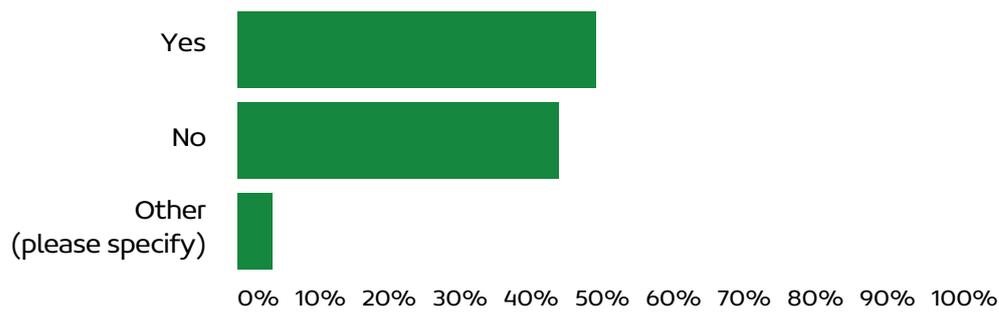


Answer Choices	Responses	
Rural	17.46%	11
Regional	34.92%	22
Metro	42.86%	27
Other (please specify)	4.76%	3
Total		63

Note: Comments showed the 4.78% responding "other" in answer to this question lived in regional/remote/rural locations.

Have you attended a pulmonary rehabilitation program?

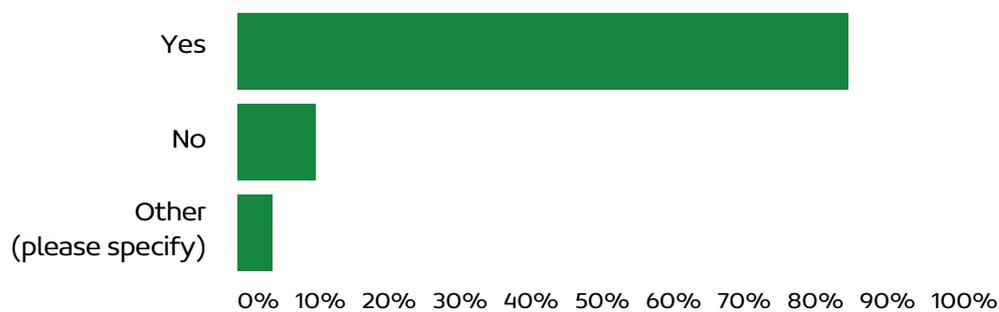
Answered: 63 Skipped: 0



Answer Choices	Responses	
Yes	50.79%	32
No	46.03%	29
Other (please specify)	3.17%	2
Total		63

Was it easy to get a referral into the program?

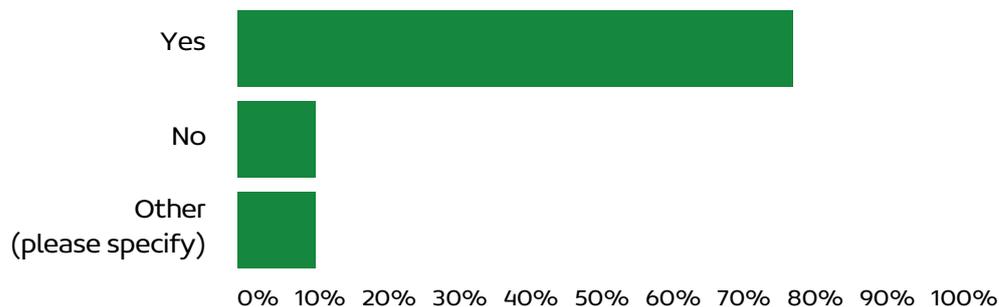
Answered: 28 Skipped: 35



Answer Choices	Responses	
Yes	85.71%	24
No	10.71%	3
Other (please specify)	3.57%	1
Total		28

Did attending the pulmonary rehabilitation program help you manage your condition?

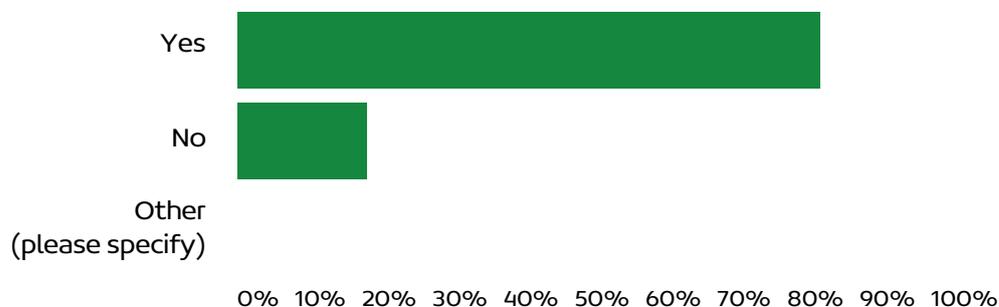
Answered: 29 Skipped: 34



Answer Choices	Responses	
Yes	79.31%	23
No	10.34%	3
Other (please specify)	10.34%	3
Total		29

Were you offered education as part of the program?

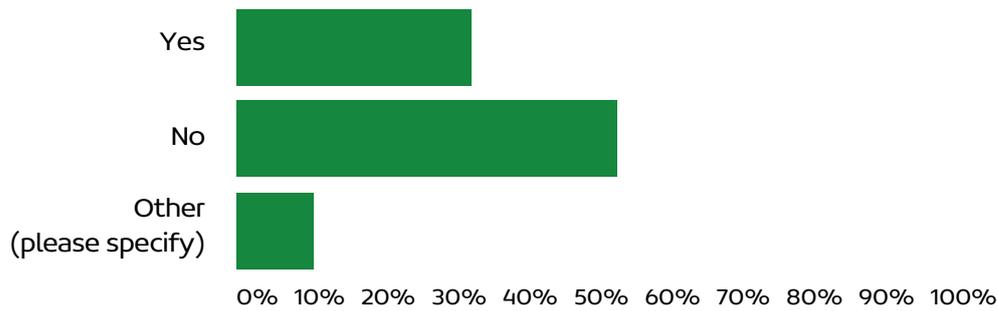
Answered: 29 Skipped: 34



Answer Choices	Responses	
Yes	82.76%	24
No	17.24%	5
Other (please specify)	0%	0
Total		29

After you completed a pulmonary rehabilitation program, were you referred onto an ongoing exercise maintenance program?

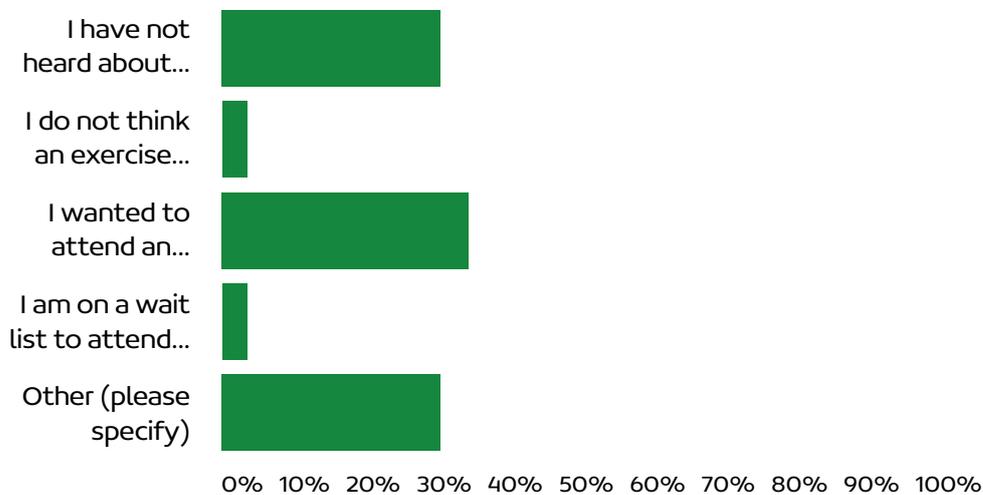
Answered: 29 Skipped: 34



Answer Choices	Responses	
Yes	34.48%	10
No	55.17%	16
Other (please specify)	10.34%	3
Total		29

What prevented you from attending a pulmonary rehabilitation program?

Answered: 27 Skipped: 36



Answer Choices	Responses	
I have not heard about pulmonary rehabilitation	29.63%	8
I do not think an exercise rehabilitation would be useful or help me manage my condition	3.70%	1
I wanted to attend an exercise rehabilitation program but there was not a service available in my local area	33.33%	9
I am on a wait list to attend a local service	3.70%	1
Other (please specify)	29.63%	8
Total		27

What would encourage or support you to attend a pulmonary rehabilitation program?

Having access to one

Some in my area

If could travel locally

Availability, reasonably close to home - I would welcome the opportunity to attend a program

Not making me feel I'm taking up the spot of someone worse than me

NDIS funding

Have my lung doctor refer me to nurse for this not just hand me a pamphlet. Have it covered totally by Medicare.

An appointment

Service close by available on days I don't work

Having a local service available

An appointment

Ease of access

Knowing if it ideal for my condition

A program that I don't need to drive 2 hours to attend.

I need more information

Recommendation from lung specialist.

Proximity and cost

Reasonable distance from home. Easier referral system.

A referral from my GP

Locality

Being free and not exercising with other people

A worsening of my lung function

Knowledge that such a thing existed in the first place, referral by health care providers. The main focus is keeping us cancer patients alive, as it should be of course, but that's all there seems to be. Nothing about exercise, rehab, nutrition, mental status etc, etc

Summary

Total of 23 responses:

Access to a local service	11 responses 47%
Funding	3 responses 12%
More knowledge about what it is	3 responses 12%
An appointment/referral	5 responses 21%
If my condition were worse	2 responses 8%

Do you have any other comments around pulmonary rehabilitation that you would like to share?

I work out at the gym most days, the personal trainer, gym workers have no idea about my condition. It would be great to have a program to suit my condition.

It is an amazing program

Only permitted to attend once per year but would like to do it on an ongoing basis. Exercise program I was referred to afterwards was not suitable.

I think it is a great idea

Would love to do another one

It was fantastic and gave me fitness and confidence as well as creating motivation for me to get fitter.

It really helped but it's difficult to keep going when the program finished.

I am in a few online groups and all reports are very positive which makes me even keener

It's not only about rehabilitation it's also about preventative measures/exercises and fitness especially when you don't know how far you should push yourself and possibly make things worse.

It definitely improves your lung function

More information

I am not sure how I would benefit from it.

My doctor suggested a Physiologist. I got 5 visits a year as a pensioner where I got a discount. The gap is still harsh, but I am on my second year now. The exercises, which I do in-between visits have strengthened my muscles and improved my breathing enormously. I have taken it upon myself to use a treadmill daily which has increased my fitness and I do tai chi at home daily which has helped regulate my breathing.

I know participating in the pulmonary rehabilitation programme certainly was a great benefit to myself & others in my group. 10 months post-transplant I still implement some of which I learnt. Totally recommend everyone to complete the programme.

It took me several attempts of 8-week program to get the understanding of why exercise was so important. Now I go every week as I am transplant candidate. I also now exercise outside of the rehabilitation class. I think the class name should be changed as rehabilitation has a negative effect to many that hear it

Do it and keep breathing

I really enjoyed Pulmonary Rehab and I found it extremely beneficial.

We were told if we wanted an exercise program to do it ourselves. Disgusting aftercare.

the course I attended was a private one - covered by Medibank. I would like a community ongoing program.

I have stage 1 lung cancer is this for me?

I have 1 session left and have found it extremely useful. The Royal Prince Alfred physiotherapists were wonderful.

People in rural areas are often overlooked when it comes to medical services. It is VERY expensive to travel and stay in accommodation in the city and it is physically exhausting

The strengthening exercise sheet was informative, and I still do them regularly.

highly recommend

Highly recommend both exercise and informational components of program. Helped me a lot.

Newly diagnosed no problem. During COVID maintenance programs closed and did not reopen in many hospitals. That has been a real problem. I wrote to my local member and the then health minister. Nothing. After waiting and trying for years I have an assessment next Tuesday. Of course, I have deteriorated in that time.

I get annoyed at the focus and funding for long COVID, but nobody cares about chronic COPD. I try to keep up. But it is getting harder. In 15 years, not ONE health professional has asked me 'how do you feel about your lung condition', not a single one. Tells me how much they care.

I would like to have the opportunity to do the program again as it is easy to slip into old sedentary habits which impact on my lung function. Maybe doing the program more than once will help with that.

Definitely beneficial to Bronchiectasis

The ongoing exercise program is quite a distance (half hour drive) away from where I live and is fairly expensive. If there was a closer, cheaper alternative I would attend far more often which I would be really grateful for.

I try to walk often with my dog but COVID has affected that for now as I have caught it

We used to have 2 sessions per week the COVID stopped gym classes but online once a week now once a week but also do exercises at home guided by DVA

I would like to see a lot more programs so there isn't a waiting list, as when you need it you can't get in

I can't really comment as it was not available to me and I found out about it quite a long way down the track.

Summary

Total of 34 comments:

Positive feedback about PR	14 responses 41%
Would like a follow-on program	11 responses 32%
Needs more information about PR	6 responses 18%
Other	3 responses 9%

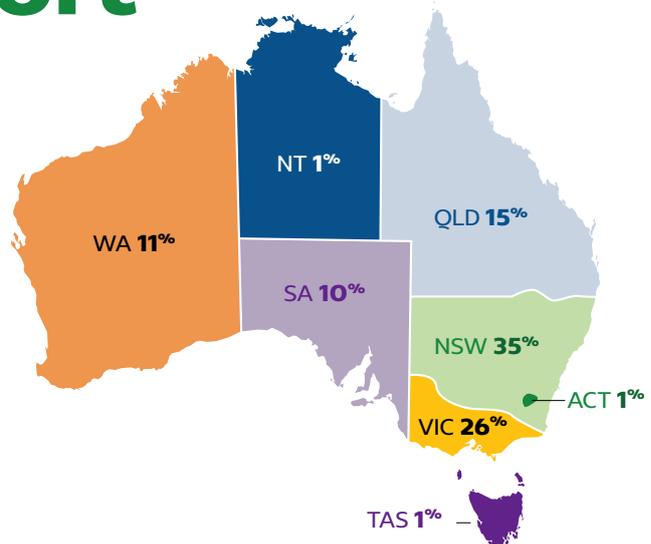
Appendix four: 2022 PR Audit summary report



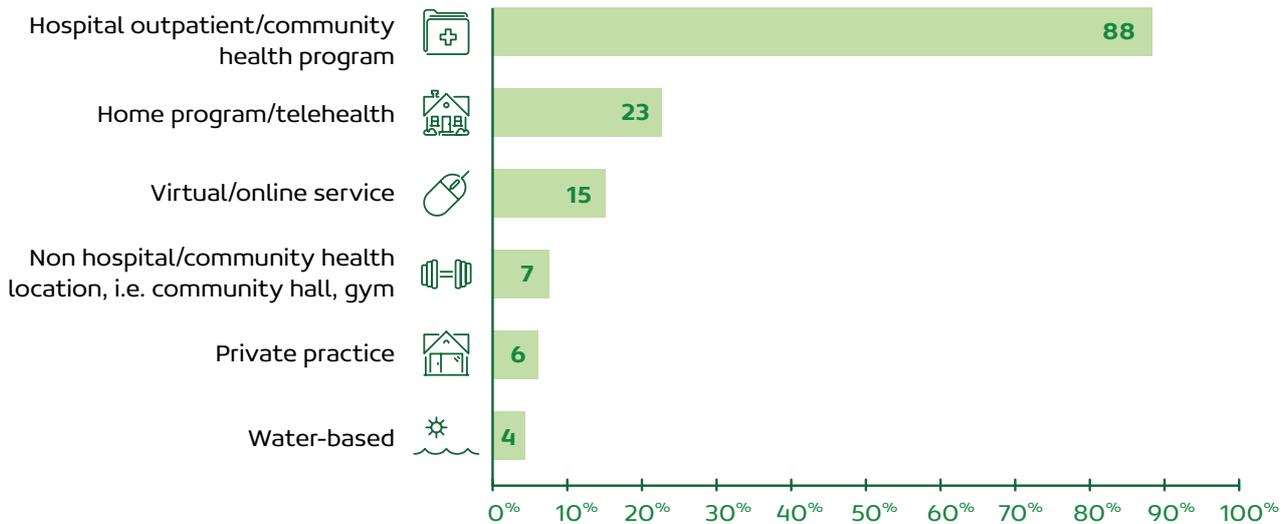
323 programs on the Lung Foundation Australia Service Directory



526 Pulmonary Rehabilitation Network Members



Program sites %



Type of health professionals involved in programs (Services selected all options that applied)

87% Physiotherapist	42% Dietitian	33% Other
62% Nurse	41% Occupational Therapist	16% Psychologist
51% Allied Health Assistant	33% Exercise Physiologist	3% Fitness Instructor/ Personal Trainer



Staff to patient ratio

43%	19%	10%	7%	4%	4%	2%	2%	2%	2%	1%	1%	1%
1:4	1:5	1:8	2:8	1:10	2:10	1:3	1:6	2:4	2:12	1:7	3:10	3:15

Referrals accepted from

(Services selected all options that applied)



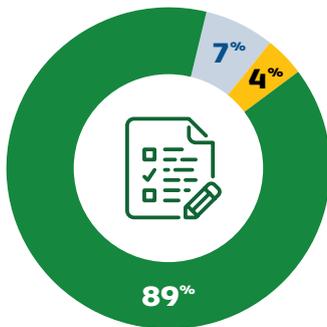
GP



Specialist



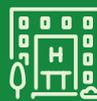
Self-referral



Conditions accepted

- All chronic lung conditions
- All conditions except lung cancer
- Other specific criteria

COVID-19



69% of services

supported patients who have been in hospital due to COVID-19



59% of programs

supported patients with long COVID



Education

Do you offer any patient education as part of your service?

80% Yes

20% No/other

Types of education sessions offered in a pulmonary rehabilitation program



84% Importance of physical exercise



75% The role and correct use of medications



83% Information on lung diseases (e.g. what the lungs do and what goes wrong with lung disease)



72% Nutrition / healthy eating



76% Coping with chronic lung disease and management of depression, anxiety and panic attacks



46% Other

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Lung Foundation Australia

Level 4, 12 Cribb Street
Milton QLD 4064

PO Box 1949, Milton QLD 4064

E: enquiries@lungfoundation.com.au

www.lungfoundation.com.au

Free call 1800 654 301

