Submission No. 112
AUTHORISED: 10/5/06

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STANDING COMMITTEE
21 MAR 2006
ON HEALTH AND AGEING

THE AUSTRALIAN LUNG FOUNDATION

Executive Summary

COPD is Australia's fourth biggest killer, estimated to cost Australian taxpayers $800-900 million each year.

This submission makes the case first for greater accessibility to key diagnostic and management techniques for Chronic Obstructive Pulmonary Disease (COPD), and second for research opportunities to fully understand the impact COPD has in Australia, both socially and economically and to bring about better health outcomes in the longer term.

The Australian Lung Foundation welcomes the opportunity to respond to this Inquiry into Health Funding, and makes six practical recommendations to lessen the cost of COPD to the health system through more effective prevention, diagnosis and management of the disease. These recommendations are as follows:

1. Improved diagnosis of COPD:
    a. Greater awareness of COPD and its symptoms among consumers (aged 45+)
    b. Greater recognition and a more effective delivery model for spirometry testing as the leading diagnostic tool - the Gold Standard - for COPD and related lung conditions. This will require:
        i. Research into how uptake of this diagnostic test can be enhanced in primary care.
        ii. Specific training programs for general practitioners and their staff.
        iii. Easier access to lung function laboratories.
        iv. Appropriate Medicare reimbursement.
2. Greater awareness and uptake of pulmonary rehabilitation, as a cost effective tool for the management of COPD and related lung conditions. Specifically:
    a. Setting a target that within two years 50 per cent of COPD patients will be participating in pulmonary rehabilitation (up from less than 1 per cent today). This will require greater awareness among healthcare professionals and a review of specific funding mechanisms to make the treatment more accessible.
    b. Improving access to smoking cessation tools after diagnosis of COPD. This could include the use of NRT on the PBS for these patients in order to support them with quitting smoking, as part of an overall "Quit" strategy.
3. Establishing a national registry of access to home oxygen in order to account for current resources, ensure that resources are consistently distributed to those most in need and identify any funding gaps which exist at a state / territory level.
4. Greater funding for research into the biologic pathways of COPD. Through this project, researchers from the The Prince Charles Hospital Foundation will explore the clinical and genetic factors that determine accelerated decline in lung function in former smokers with COPD. The results of this three-year research project may assist healthcare professionals to better assess an individual's susceptibility to COPD and whether that COPD would be mild, moderate or severe.
5. Extending current epidemiological research into COPD, in order to better understand the extent of the problem in Australia and the impact of an ageing population.
6. Greater support for Self-Help Patient Support Groups, of which there are currently 120 with 15,000 members in total. On current incidence rates, there is potential demand for up to 1,000 of these groups. The ALF currently expends $300,000 per year to service its 120 groups, and community education is likely to stimulate further demand in the short term.

The Australian Lung Foundation (ALF) is a national, not-for-profit Non Government Organisation - founded by clinicians in 1990 - that seeks to promote lung health, facilitate research and improve the delivery of diagnostic services and effective management for COPD and related lung conditions. Through fundraising, the ALF has been able to invest over $5 million in these activities. In clinical education for example, the ALF has developed best practice management guidelines, the COPD checklist, an action plan, and a toolkit and guidelines for pulmonary rehabilitation.

Section 1: A Definition of COPD and Related Issues

COPD is a lung disease that affects one in six Australians over 45.[1] While there is no cure there are things people can do to breathe easier and improve their quality of life, particularly if it is identified and managed early.

What is COPD?

- Chronic Obstructive Pulmonary Disease (COPD) is a long term disease of the lungs which causes shortness of breath.[2] It is not fully reversible.[3]
- COPD is characterised by:
  - Shortness of breath on minimal exertion
  - A repetitive cough with phlegm / mucus most days
  - History of cigarette smoking

Figure One: Close up of airway and air sacs

Normal lungs: each airway is clear and open and each air sac fills up with air which then goes quickly out.

Lungs damaged by COPD: the openings of the airways are smaller and air sacs cannot empty, causing shortness of breath.

What Causes COPD?

- Cigarette smoking is the single largest cause of developing COPD.[4] However despite being the highest risk group for COPD, regular smokers are less likely than the rest of the population to consider themselves at risk of developing COPD[5].
- Other known risk factors are passive smoking, exposure to environmental agents, including indoor and outdoor air pollutants and occupational dusts and chemicals.[6]
- Women may be at greater risk than men of COPD from exposures at work and are more susceptible to COPD due to smaller lungs and airways and more sensitive airways.[7]

Prevalence of COPD

- The Australian Lung Foundation estimates that approximately one million Australians have COPD,[8] with a recent study finding that up to one in six Australians over 45 have the condition.[9]
- As many as three in four Australians with COPD are unaware that they even have the disease,[10] which means they are not taking the important steps to manage the condition before it reaches a more advanced and debilitating stage. People may mistake their symptoms as signs of ageing or of asthma - a simple lung function test from a GP can diagnose COPD.

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[1] Abramson MJ. Respiratory symptoms and lung function in older people with asthma or chronic obstructive pulmonary disease. MJA 4 July 2005;**183**(1):S23-S25

[2] Tashkin DP, Clark VA, Coulson AH *et al.* The UCLA population studies of chronic obstructive respiratory disease. VIII. Effects of smoking cessation on lung function: a prospective study of a free-living population. *Am Rev Respir Dis* 1984;**130**: 707-15

[3] *Ibid*

[4] *Ibid*

[5] Pfizer Health Report, Issue 23 *Healthy Breathing*, p 3 (www.healthreport.com.au)

[6] McKenzie DK, Frith PA, Burdon *et al.* COPD: Australian and New Zealand management guidelines and the COPD handbook. *MJA* 17 March 2003;**178**(6): S1-S40 and NHLBI/WHO Workshop Report. Global Initiative for Chronic Obstructive Lung Disease (GOLD): Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease. Bethesda, MD: National Institutes of Health - National Heart, Lung and Blood Institute, April 2001

[7] Petty T. The Rising Epidemic of COPD in Women Why women are more susceptible; how treatment should differ. *Women's Health in Primary Care* Dec 1999;**2**(12)

[8] The Australian Lung Foundation Advocacy document. September 2004

[9] Abramson MJ. Respiratory symptoms and lung function in older people with asthma or chronic obstructive pulmonary disease. MJA 4 July 2005;**183**(1):S23-S25

[10] Frith P. Prevalence and Treatment of Chronic Obstructive Pulmonary Disease (COPD) in Australia. Australian Lung Foundation, Nov 2004

The Burden of COPD

- COPD is Australia's fourth biggest killer, and the third leading cause of disease burden, after heart disease and stroke[11] - but it is still not a health priority area in Australia.
- It is estimated that COPD costs Australia $800-900m annually, and it is likely that the actual economic burden is a lot higher due to misdiagnosis of COPD.[12]
    - In fact, every day 1,000 COPD patients occupy Australian hospital beds, with an average cost of $3,700 per admission (average 7.5 day stay).[13]

COPD Prevention and Treatment

The key aims of COPD treatment are to improve quality of life, increase the capacity for exercise and ultimately, reduce morbidity. There is no cure for COPD, however there are a number of steps people with COPD can take to improve the length and quality of their lives:

- Stop smoking - helps improve symptoms and slow down the rate the disease progresses.
- Reliever inhalers and some other medications - make the airways wider and help make breathing easier.
- Pulmonary rehabilitation - suitable exercises help relieve some of the breathlessness and improve a patient's ability to be more active. It has also been designed to meet patients' physical, emotional and social needs.
- Support groups/services - as COPD worsens and patients feel less able to carry on their normal activities, patients become increasingly isolated. Support groups/services help meet the emotional and social needs of people with the condition, helping them realise that they are not alone.
- Oxygen therapy - helps people with advanced lung disease to get the extra oxygen that they need and be more active. It may also prevent some of the complications of COPD.
- People over 45 should see their GP about a simple lung function test if they have any of the symptoms of COPD:
    - Shortness of breath compared with others their age
    - A repetitive cough with phlegm / mucus most days
    - Smoke or an ex smoker

Statistical Gaps in the Study of COPD

The statistics above are quite striking. However, a challenge for those with an interest in COPD is the lack of an agreed national data set, providing a reliable incidence rate across Australia. While many individual studies suggest a very high prevalence of COPD in Australia, there is no national data to authoritatively establish this on a national level. Similarly, there is a lack of clarity on the differing rates of COPD in metropolitan and non-metropolitan Australia.

Together with the Woolcock Institute of Medical Research, the ALF has embarked on an important first step towards collecting definitive national data on the prevalence and costs of COPD in Australia. The BOLD (Burden of Obstructive Lung Disease) project is a recognised international research protocol designed to collect high quality, country specific data on COPD using standardised testing methods.

Currently the project is being implemented in the Sydney area with results expected in the latter part of 2006. Together the Woolcock and the ALF have raised $180,000 to implement this project plus an additional $110,000 US dollars "in kind" support from the BOLD collaborative centre in the United States. However, in order to gain a national insight into the impact of COPD an additional three study centres will be required in addition to the current metropolitan (Sydney) centre: urban, rural and remote.

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[11] Mathers C, Vos T, Stephenson C. 1999 The Burden of Disease and Injury in Australia. ISBN 1-74024-019-7. AIWH Cat. No. PHE-17
[12] Crockett AJ, Cranston JM, Moss JR. Economic Case Statement. Chronic Obstructive Pulmonary Disease. Australian Lung Foundation, Sept 2002
[13] *Ibid*

Section 2: The Australian Lung Foundation

The ALF is a national, not-for-profit organisation that leads the promotion of lung health in Australia. It promotes clinical education, community awareness, research and facilitates patient support throughout Australia. Formed by a group of physicians in 1990, The Australian Lung Foundation now provides Medical and Self-help Patient Support Group services in every State and Territory.

The key functions of the ALF are as follows:

- Educating and supporting clinicians at both primary and secondary levels;
- Raising funds to support increased medical research into lung disease;
- Distributing research findings and knowledge;
- Educating patients and the broader public on the treatment and prevention of lung disease;
- Fostering Patient Support Activities and promoting self management techniques for COPD management;
- Influencing public and corporate policy to ensure a safe living and working environment.

In its fifteen-year history, the ALF has made a significant contribution to the awareness, management and relief of lung disease in Australia. It should be noted that the ALF has already raised funds and invested over $5 million into programs covering clinical education and research.

A good example of the ALF contribution is LungNet, a tangible network for lung patients and their carers. The LungNet is not a patient support group, but a network of affiliated support groups across Australia comprising 120 groups and over 15,000 patients and their families and caregivers.

LungNet provides the following services to patient support groups and their members:

- Managing a toll free help line service to provide information on lung health and contact details for patient support and pulmonary rehabilitation throughout Australia;
- Assisting new groups to form where needed by providing guidance and set-up financial assistance;
- A national clearing-house for producing and distributing patient education information;
- A national LungNet newsletter informing patient support group members of national issues and the activities of groups in other states;
- A communications link between patient support groups;
- A point of contact for group members with other groups when they travel and require "away from home" support;
- National initiatives from time to time for member enjoyment and participation;
- A medium for patient support groups to participate in the promotion of lung health at a national level;
- Education seminars for patients with COPD

Patient support groups or patients do not pay any fees to be affiliated with LungNet. The LungNet simply exists to ensure patients can access and enjoy the benefits of a continuity of patient support Australia wide.

Services provided by the LungNet directly to patients, such as the Toll Free 1800 654 301 information and referral assistance, and the national newsletter, are also free of charge to patient support group members. Through LungNet, the ALF is providing an invaluable and significant service to lung patients and their carers across Australia.

Section 3: Diagnostic and Treatment Issues

Diagnosis: Spirometry Testing

COPD is often misdiagnosed, and commonly mistaken for asthma, resulting in COPD being under-treated.[14] A research study undertaken in 2004 closely followed a sample of 385 smokers, on the basis that smoking is the most important risk factor for COPD. Lung tests were conducted on 283 of the patients, and while 88 fulfilled the diagnostic criteria for COPD, only 9 were aware of it.[15] Failure to diagnose COPD means effective treatment will not be made available in the most efficient and effective ways. From the perspective of the ALF, early diagnosis is the key to improving people's lifestyle and health outcomes.

The most effective tool to diagnose COPD is spirometry testing. Spirometry measures the volume of air entering and leaving the lungs, assisting with the diagnosis and management of many diseases affecting the lungs such as asthma, COPD and restrictive disorders. During the test patients put a mouthpiece in their mouth and perform various breathing maneuvers: taking a deep breath, holding it briefly, and forcefully blowing the air out through the mouthpiece, which is attached to a device that performs the measurements.

Combined with knowledge of a patient's smoking history, spirometry testing provides an essential diagnostic function in the identification and subsequent management of COPD. The Frith study above went on to find that 'better and differential diagnostic methods appear to be needed for respiratory symptoms in adults with a smoking history, and spirometry can be considered an essential tool for both confirming a diagnosis of COPD and differentiating whether such patients have asthma or COPD'.[16]

However, the accessibility and quality of spirometry testing in GP surgeries is highly inadequate. In New Zealand - where use of spirometry testing in primary care is similar to Australia - a study of 30 primary care practices found that acceptable and reproducible spirometry was met 3.4% of the time when practices relied purely on the spirometer manual as 'training', increasing to 13.5% of the time when the operators had received only a brief training session.[17]

Anecdotal reports from GPs suggest that it is difficult to incorporate spirometry into the consultation, and there have been variable outcomes after systematic efforts to teach optimal performance of the test.[1819] There are many reasons for this, including the complexity of properly performing the test, the cost of equipment, the time taken to perform bronchodilator reversibility testing, and controversy regarding interpretation of results.[20]

Combined with an understanding of a patient's smoking history, reliable spirometry testing better enables GPs to distinguish COPD from asthma or related conditions. As such, more available and reliable spirometry testing - as well as properly trained staff - is a critical element in the improvement of diagnosis and management for COPD in Australia.

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[14] Matheson MC, Abeysena C, Raven JM *et al.* How have we been managing chronic obstructive pulmonary disease in Australia? *Int Med J* 2006;**36**:92-99

[15] Frith P. 'Chronic Obstructive Pulmonary Disease (COPD) in Australia: An under-recognised and under-treated burden'. Report for the Australian Lung Foundation, 17 November 2004

[16] *Ibid.*, p.38

[17] Eaton T, Withy S, Garrett JE, *et al.* Spirometry in primary care practice: the importance of quality assurance and the impact of spirometry workshops. *Chest* 1999;**116**(2): 416-423

[18] *Ibid*

[19] Schermer TR, Jacobs JE, Chavannes NH *et al.* Validity of spirometric testing in a general practice population of patients with chronic obstructive pulmonary disease (COPD). *Thorax* 2003; **58**: 861-866

[20] Jenkins C, Young I. Assessing bronchodilator reversibility: agreed standards are urgently needed. *MJA* 21 June 2004;**180**: 605-606

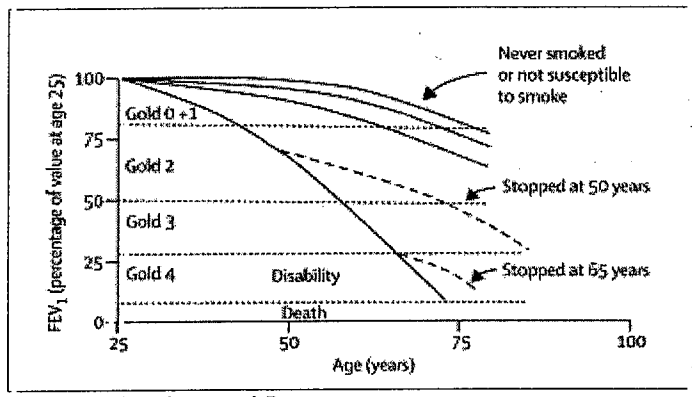
Treatment: Pulmonary Rehabilitation

Pulmonary rehabilitation is an umbrella term that encompasses exercise training and access to a multidisciplinary team to provide education about lung disease and its management, smoking cessation, nutritional advice, individual physiotherapy advice, psychological interventions to manage problems such as anxiety and depression, occupational therapy and end of life planning. It is evident that pulmonary rehabilitation provides a broad, holistic approach to the management of lung disease in response to its multi-faceted impacts. Pulmonary rehabilitation provides a proven framework to manage COPD symptoms using recognised self management techniques. The Pulmonary Rehabilitation Toolkit, to be launched on 25 March 2006, aims to increase accessibility of pulmonary rehabilitation in Australia. It provides a detailed explanation of the elements of pulmonary rehabilitation so that interested health professionals can equip themselves to set up a program locally, whether they are in an urban centre or remote township. The Toolkit can be viewed at www.pulmonaryrehab.com.au.

i. Smoking cessation

Smoking cessation is proven to slow the progression of COPD[21] and is therefore critical. Figure Two illustrates that smoking cessation gradually tends to return the rate of declining lung function to that of never-smokers.[22] It is estimated that 90 per cent of the health care costs of COPD for men and 80 per cent for women are attributable to smoking alone.[23] However, even after diagnosis with COPD, many patients struggle to quit smoking.

Figure Two: Impact of Smoking upon Lung Volume



Source: Fletcher and Peto

The National Prescribing Service recommends that 'nicotine replacement therapy (NRT) is the most effective pharmacotherapy to help smokers quit',[24] however for many people diagnosed with COPD it remains out of reach because of cost. Through enabling cheaper access to NRT therapies - for instance making it available on the PBS for people diagnosed with COPD - more may be able to quit, leading to better health outcomes and less pressure on public health funding.

ii. Exercise and Support

The aims of pulmonary rehabilitation are to 'reduce disability and handicap and to improve quality of life while diminishing the health care burden in people with chronic lung disease'.[25] It is estimated that individuals with COPD comprise 80 per cent of the participants in most pulmonary rehabilitation programs.

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[21] National Prescribing Service. NPS News. August 1999. ISSN 1441-7421. Found at: http://www.nps.org.au/resources/NPS_News/news05/news05.pdf

[22] *Ibid.*

[23] Crockett AJ, Cranston JM, Moss JR. *Economic Case Statement: Chronic Obstructive Pulmonary Disease (COPD).* Australian Lung Foundation, September 2002, p.21

[24] National Prescribing Service. *OpCit*

[25] Crockett AJ, Cranston JM, Moss JR. *OpCit* p.21

Studies have shown that pulmonary rehabilitation programs can add to the quality of life of patients with COPD.[26] Anecdotal Australian experience has found that individuals involved in a pulmonary rehabilitation exercise program can reduce the number of hospitalisations and the duration of hospital visits. This is supported by international data from the UK[27] and Canada[28], both of which found pulmonary rehabilitation to be cost effective and associated with 'decreased health service utilization, reduced direct costs and improved health status of COPD patients'[29].

In Australia, most pulmonary rehabilitation programs are offered in an out-patient setting (most within the physiotherapy department of a public hospital) with patients attending usually two sessions per week for an average of 6-10 weeks. The benefits of pulmonary rehabilitation decline over a 12-18 month period following cessation of a supervised program and thus maintenance programs in the community, and for the most disabled patients within the hospital setting, are required. In their year-long, 200-patient trial Griffiths *et al* found that 'for patients chronically disabled by obstructive pulmonary disease, an intensive, outpatient programme of rehabilitation is an effective intervention, in the short term and the long term, that decreases use of health services'.[30]

The NPS advocates integrated programs which include education, exercise, behaviour modification and support as being 'more effective than individual components used separately'.[31] A meta-analysis of 65 studies found that comprehensive pulmonary rehabilitation programs can improve multiple measures of functioning and well-being of adults with COPD. The accuracy in performing psychomotor skills (e.g. inhaler use) can be improved through education; and relaxation has been shown to reduce psychological distress and dyspnoea.[32]

However, access to pulmonary rehabilitation is highly inadequate. The ALF estimates that less than 1 per cent of patients with COPD currently receive pulmonary rehabilitation. In many cases, referral to a pulmonary rehabilitation program is often restricted to those referred by a respiratory physician - and not those treated by GPs. Further, there is also limited access to maintenance programs. The reasons for this are unclear and we are keen to explore the veracity of this further. More simply, there also appears to be a lack of programs available across Australia.

Through pulmonary rehabilitation, Australia's health decision-makers have access to an innovative, proven, cost-effective treatment for COPD that is underutilised under the current arrangements. To this point, they have missed out on the benefits that pulmonary rehabilitation can offer the health system. Unfortunately, patients have also missed out on the benefits the technique can bring to their lives.

Treatment: Home Oxygen

Apart from smoking cessation, the provision of home oxygen is the only therapy shown to reduce mortality in people with severe COPD.[3334] There is also evidence that it supports a number of other health outcomes including exercise performance and capacity to undertake the activities of daily living.[35]

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[26] National Prescribing Service. *OpCit*
[27] Griffiths TL, Phillips CJ, Davies S *et al.* Cost effectiveness of an outpatient multidisciplinary pulmonary rehabilitation programme. *Thorax* 2001;**56**:779-784
[28] Golmohammadi K, Jacobs P, Sin DD. Economic evaluation of a community-based pulmonary rehabilitation program for chronic obstructive pulmonary disease. *Lung* 2004;**182**:187-196
[29] *Ibid*
[30] Griffiths T L, Burr M L, Campbell I A *et al. OpCit*
[31] National Prescribing Service. *OpCit*
[32] Devine EC, Pearcy J. *Patient Education and Counseling* 29(2): pp.167-168. In: The Cochrane Library
[33] Nocturnal Oxygen Therapy Trial Group. Continuous or nocturnal oxygen therapy in hypoxemic chronic obstructive lung disease: a clinical trial. *Ann Intern Med* 1980;**93**: 391-398
[34] Report of the Medical Research Council Working Party. Long-term domiciliary oxygen therapy in chronic hypoxic cor pulmonale complicating chronic bronchitis and emphysema. *Lancet* 1981;1:681-686
[35] Standards for the diagnosis and care of patients with chronic obstructive pulmonary disease. ATS Official Statement. *Am J Respir Crit Care Med* 1995;**152** Suppl: 77-120

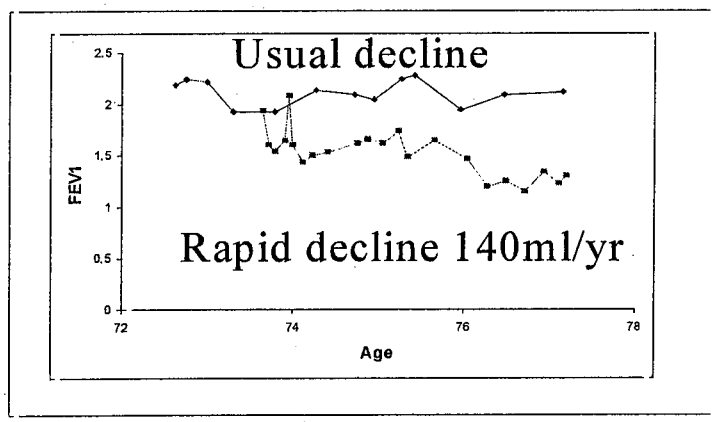
Home oxygen is generally advocated for people with advanced COPD, when undertaking simple tasks become very difficult because of a loss of lung function. In a position statement by the Thoracic Society of Australia and New Zealand (TSANZ) Young *et al* conclude 'evidence shows that patients with chronic obstructive pulmonary disease [who have reduced levels of oxygen in their blood] ... will have longer life expectancy if given supplemental oxygen ... preferably for longer than 15 hours a day, including sleep'.[36]

Unfortunately there are currently significant inequalities in access to home oxygen across Australia (see Appendix One). Subsidies for home oxygen vary greatly from state to state, with some states offering reasonably generous assistance to others that provide no subsidy whatsoever for portable oxygen.

Understanding Genetic Predispositions for COPD

As outlined above, smoking cessation is proven to slow the progression of COPD. However, while most patients benefit from smoking cessation at any time, some successful quitters will still experience accelerated decline in their lung function. Figure Three illustrates the clinical experiences of two successful Australian quitters, one of whom followed the usual decline of a quitter as outlined by Fletcher and Peto (see Figure Two), while the other experienced more rapid decline.

Figure Three: Case Study – Lung Decline of Two Australians



Source: I Yang, The Prince Charles Hospital Foundation (Qld)

Australia has already embarked on some exciting research at The Prince Charles Hospital Foundation into the biologic pathways of COPD, with the intention of identifying clinical and genetic factors determining accelerated decline in lung function in former smokers with COPD. However, there are limitations to the current research due to funding. If additional funding was available the initiative could be extended to fully understand potential mechanisms and strategies for preventing COPD progression in former smokers.

[36] Young IH, Crockett IJ, McDonald CF. Adult domiciliary oxygen therapy: a position statement by the Thoracic Society of Australia and New Zealand. *MJA* 1998;**168**: 21-25

Section 4: Recommendations to the Inquiry into Health Funding

This submission responds directly to the following terms of reference for the Inquiry into Health Funding:

- How the Commonwealth government can take a leading role in improving the efficient and effective delivery of highest-quality health care to all Australians;

- Examining the roles and responsibilities of the different levels of government (including local government) for health and related services;

- Simplifying funding arrangements, and better defining roles and responsibilities, between the different levels of government, with a particular emphasis on hospitals and primary care.

As such, the ALF makes six recommendations to the Inquiry into Health Funding:

1. Improved diagnosis of COPD:
   a. Greater awareness of COPD and its symptoms among consumers (aged 45+)
   b. Greater recognition and a more effective delivery model for spirometry testing as the leading diagnostic tool - the Gold Standard - for COPD and related lung conditions. This will require:
      i. Research into how uptake of this diagnostic test can be enhanced in primary care.
      ii. Specific training programs for general practitioners and their staff.
      iii. Easier access to lung function laboratories.
      iv. Appropriate Medicare reimbursement.

2. Greater awareness and uptake of pulmonary rehabilitation, as cost effective tool for the management of COPD and related lung conditions. Specifically:
   a. Setting a target that within two years 50 per cent of COPD patients will be participating in pulmonary rehabilitation (up from less than 1 per cent today). This will require greater awareness among healthcare professionals and a potential review of the role Medicare could play to make the treatment more accessible.
   b. Improving access to smoking cessation tools after diagnosis of COPD. This could include the use of NRT on the PBS for these patients in order to support them with quitting smoking.

3. Establishing a national registry of access to home oxygen in order to account for current resources, ensure that resources are consistently distributed to those most in need and identify any funding gaps which exist at a state / territory level.

4. Greater funding for research into the biologic pathways of COPD. Through this project, researchers from the The Prince Charles Hospital Foundation will reach an endpoint to predict an individual's susceptibility to COPD and whether that COPD would be mild, moderate or severe.

5. Extending current epidemiological research into COPD, in order to better understand the extent of the problem in Australia and the impact of an ageing population.

6. Greater support for Self-Help Patient Support Groups, of which there are currently 120 with 15,000 members in total. On current incidence rates, there is potential demand for up to 1,000 of these groups. The ALF currently expends $300,000 per year to service its 120 groups, and community education is likely to stimulate further demand in the short term.

The Australian Lung Foundation is keen to discuss these matters in greater detail with decision-makers and would gladly attend a public hearing if the Committee has any questions on the contents of this submission. Please let us know if we can assist in any way.

Appendix One: Access to Home Oxygen Across Australia

Figure Four: Inconsistencies in Access to Home Oxygen Across Australia (as at November 2005)

	ACT	NSW	NT	QLD	SA	TAS Sth	TAS Nth	VIC	WA	DVA
How long between reviews?	✚	f	♠	3-4 mths	✪	✚	☆	✚	☆	☆

All concentrators are free once the means test has been satisfied.

Subsidised portable oxygen available for home use?	Yes ✿	No	Yes	No	Yes	Free	Yes	Yes ◆	-	Free
Number of portable cylinders (per month)	2 ▲	1	1	0	4	1	2 ❄	4 – 8	3-4	1 ☐

✚ Annually by a specialist

✿ If more than two a month are required, a conservation device is provided before more cylinders are given at subsidised rates

▲ Based on need, but 2 is usual

f 1 month after hospital discharge and then yearly

☆ Each patient is treated as an individual

❄ Usually 2, sometimes more

❖ A trolley/carry bag and the appropriate consumables also at no cost. Most patients are supplied with an oxygen conserving device (also free of charge).

◆ $200 per month for equipment and gas - this ceiling applies whether or not they qualify for a concentrator. In addition to a concentrator, this might add up to 4 portable cylinders per month. Without a concentrator, this may be around 8 cylinders per month (irrespective of cylinder size), and can include a conservation device.

♣ This will be become Australia wide in the near future, but may be different across the states at this time.

☐ More is available if required

✪ Each patient is treated as an individual. At one centre, oxygen patients are seen approximately 1 month after commencing home oxygen and then in clinic approx 6 monthly but are reviewed by Respiratory nurses every 3 months, usually by a phone call. However, other hospitals may not follow up their patients.

♠ Clients were every 3/12 but due workload are now review annually. Very few clients get medical reviews, whatever they get prescribed in the start is what they usually stay on until things deteriorate and they increase little by little.