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Monitoring pulmonary rehabilitation and long-term oxygen therapy for people with chronic obstructive pulmonary disease (COPD) in Australia

A discussion paper

WOOLCOCK
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ACAM
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Asthma Monitoring



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Health and Welfare**

*Authoritative information and statistics
to promote better health and wellbeing*

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Australian Institute of Health and Welfare
Canberra

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Abbreviations

ABS	Australian Bureau of Statistics
ACAM	Australian Centre for Asthma Monitoring
AIHW	Australian Institute of Health and Welfare
BEACH	Bettering the Evaluation and Care of Health
BOLD	Burden of Obstructive Lung Disease
COPD	chronic obstructive pulmonary disease
IHPA	Independent Hospital Pricing Authority
IRSD	Index of Relative Socio-Economic Disadvantage
LFA	Lung Foundation Australia (formerly the Australian Lung Foundation)
LHN	Local Hospital Network
LTOT	long-term oxygen therapy
NAP DSS	Non-Admitted Patient Dataset Specification
NHCCN	National Health Call Centre Network
NHMD	National Hospitals Morbidity Database
NHSD	National Health Service Directory
NOCD	National Outpatient Care Database
NSW	New South Wales
SEIFA	Socio-economic Indexes For Areas
TSANZ	Thoracic Society of Australia and New Zealand
VicHSD	Victorian Human Services Directory
WHO	World Health Organization

Symbols

p_aO_2	partial pressure of oxygen in the arterial blood (a measure of the amount of oxygen in the blood)
SaO_2	percentage of available haemoglobin that is saturated with oxygen (a measure of the concentration of oxygen in the blood)
mm Hg	millimetres of mercury
✓	recorded
✗	not recorded

Summary

Chronic obstructive pulmonary disease (COPD) is a major cause of death and disability in Australia. About 1 in 13 people aged 40 and over have lung function consistent with a diagnosis of COPD (Toelle et al. 2013). The disease develops over many years and therefore mainly affects middle-aged and older people. Smoking is its main, but not only, cause.

Current clinical guidelines for the management of COPD (developed by the Thoracic Society of Australia and New Zealand and Lung Foundation Australia) emphasise the importance of care that encompasses both drug and non-drug based interventions designed to improve quality of life and survival.

Pulmonary rehabilitation is a system of care that includes a combination of exercise, education and psychosocial support. It has been shown to have a wide range of beneficial effects, particularly because of its exercise component. Pulmonary rehabilitation implemented after a hospital admission reduces the risk of re-hospitalisation and death, and improves quality of life.

Selective use of long-term oxygen therapy (LTOT) – the provision of supplemental oxygen therapy for 15 hours per day or more for people with COPD who have persistently low levels of oxygen in their blood – has been shown to improve quality of life and improve survival.

Both of these therapies are among the key non-pharmacological interventions recommended in national and international clinical guidelines. Available evidence suggests, however, that pulmonary rehabilitation and LTOT are under-utilised in managing patients with COPD in Australia. The full extent of service provision, utilisation and under-utilisation is not known as there are no national data.

This report outlines:

- proposed indicators relevant to monitoring access to, and utilisation of, pulmonary rehabilitation and LTOT in Australia
- existing data sources that may inform these indicators
- options for data development
- potential challenges in monitoring these therapies.

Improved information about access to, and use of, these interventions among people with COPD would enable:

- identification of opportunities for health improvement
- measurement of the benefits derived from these interventions.

This would form a useful basis for data development to support assessment of the appropriateness of use, barriers to uptake and outcomes of these therapies.

Similar information about the provision of non-inpatient, non-procedural and non-pharmaceutical therapies is also relevant to monitoring other chronic diseases in which these interventions improve quality of life and extend life.

1. Introduction

Chronic obstructive pulmonary disease (COPD) is a serious long-term lung disease that mainly affects middle-aged and older people (ACAM 2011; Toelle et al. 2013). It is a progressive disease and is largely irreversible, often leading to impaired quality of life and sometimes to premature death. Although it is difficult to precisely determine its prevalence, a large international study estimated that about 1 in 13 Australians aged 40 and over have lung function consistent with a diagnosis of COPD (Toelle et al. 2013).

The most important risk factor for COPD is smoking (Anthonisen et al. 1994; Doll & Peto 1976). As smoking has historically been more common in men than women, COPD has been more common in men but the difference is declining in Australia (ACAM 2011). Rates of hospital separation for COPD are higher among Aboriginal and Torres Strait Islander people than among non-Indigenous Australians (ACAM 2011).

COPD is a major cause of death in Australia. In 2011, 5,878 people were recorded as having died from COPD (3,278 males and 2,600 females), making it the fifth leading cause of death (ABS 2013).

Direct health expenditure attributed to COPD was \$929 million in the 2008–09 financial year, accounting for 1.3% of all health care expenditure in that year (AIHW 2010). Health expenditure for COPD may rise as the population ages and the number of people with the disease increases.

In response to the significant burden the disease represents, the Thoracic Society of Australia and New Zealand and Lung Foundation Australia jointly developed and regularly revised, the COPD-X Plan, guidelines on the diagnosis and management of COPD (Abramson et al. 2013; McDonald et al. 2005). The aim of these guidelines was to shift the emphasis of care to encompass both pharmacological and non-pharmacological interventions that are designed both to improve quality of life and to extend life for people with COPD (Abramson et al. 2013). Pulmonary rehabilitation and selective use of long-term (home) oxygen therapy (LTOT) are among the key non-pharmacological interventions recommended in the COPD-X guidelines (Box 1.1) and are the focus of this report.

Previous reports have highlighted the apparent under-utilisation of pulmonary rehabilitation and long-term oxygen therapy in the management of patients with COPD in Australia (ALF 2007; Serginson et al. 2009). These reports imply that further data may be needed to address this problem and to realise opportunities for health gain in this arena.

Box 1.1: Summary of guidelines relevant to the use of pulmonary rehabilitation and long-term oxygen therapy in patients with COPD

COPD-X Plan, Australian and New Zealand Guidelines for the management of COPD (Abramson et al. 2013)

- Pulmonary rehabilitation reduces dyspnoea, fatigue, anxiety and depression, improves exercise capacity, emotional function, health-related quality of life and enhances patients' sense of self control over their condition.
- Pulmonary rehabilitation should be offered to patients with moderate to severe COPD.
- Pulmonary rehabilitation reduces hospitalisation and has been shown to be cost-effective.
- LTOT (≥ 15 hours/day) prolongs life in hypoxaemic patients (arterial oxygen tension (p_aO_2) < 55 mm Hg).

GOLD (Global Initiative for Chronic Obstructive Lung Diseases), Global strategy for the diagnosis, management and prevention of COPD (GOLD 2013)

- All patients who get short of breath when walking on their own pace on level ground should be offered [pulmonary] rehabilitation.
- The long-term administration of oxygen (> 15 hours per day) to patients with chronic respiratory failure has been shown to increase survival in patients with severe resting hypox[a]emia. LTOT is indicated for patients who have:
 - a) p_aO_2 at or below 55 mm Hg or SaO_2 at or below 88% with or without hypercapnia confirmed twice over a three week period or
 - b) p_aO_2 between 55 mm Hg and 60 mm Hg, or SaO_2 of 88%, if there is evidence of pulmonary hypertension, pulmonary [o]edema suggesting congestive cardiac failure or polycyth[a]emia.

American Thoracic Society/European Respiratory Society Taskforce, Standards for the diagnosis and treatment of patients with COPD (Celli et al. 2004)

- Pulmonary rehabilitation results in improvements in multiple outcome areas of considerable importance to the patient, including dyspnoea, exercise ability, health status and health care utilisation.
- Pulmonary rehabilitation should be considered for patients with COPD who have dyspnoea or other respiratory symptoms, reduced exercise tolerance, a restriction in activities because of their disease, or impaired health status.
- Pulmonary rehabilitation programs include exercise training, education, psychosocial/behavioural intervention, nutritional therapy, outcome assessment and promotion of long-term adherence to the rehabilitation recommendations.
- Supplemental LTOT improves survival, exercise, sleep and cognitive performance in hypoxaemic patients.
- Physiological indications for oxygen include $p_aO_2 < 55$ mm Hg. The therapeutic goal is to maintain $SaO_2 > 90\%$ during rest, sleep and exertion.
- If oxygen is prescribed during an exacerbation, arterial blood gases should be rechecked in 30–90 days.

What is pulmonary rehabilitation?

Pulmonary rehabilitation is a system of care that includes a combination of exercise, education and psychosocial support. Individuals with COPD accounted for the largest proportion of people being referred for pulmonary rehabilitation (Nici et al. 2006).

Pulmonary rehabilitation is defined as:

'..an evidence-based, multi-disciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities. Integrated into the individualized treatment of the patient, pulmonary rehabilitation is designed to reduce symptoms, optimize functional status, increase participation, and reduce health care costs through stabilizing or reversing systemic manifestations of the disease.' (Nici et al. 2006; Ries et al. 2007)

The combination of these interventions is important because COPD is a complex, multi-system disease with resulting physical deconditioning, emotional responses to illness and social isolation, that can contribute to greater morbidity (Lacasse et al. 2006).

Pulmonary rehabilitation programs are targeted at people who have chronic lung disease and who have symptoms of breathlessness or fatigue on exertion.

The primary aims are to:

- reduce activity limitation and participation restriction of persons with chronic lung diseases
- restore patients to the highest possible level of independent functioning (Alison et al. 2009).

Exercise therapy within the scope of a pulmonary rehabilitation program should include lower limb endurance training and a home-based program. Ideally, the program should also include lower limb strength training and upper limb endurance and strength training (Alison et al. 2009) and should be provided in combination with patient education.

Education for people with COPD, which may be provided in written, audio or video formats, usually covers smoking cessation, improving exercise capacity, nutrition, instruction on effective use of medication inhaler devices, development of action plans for exacerbations, coping strategies for activities of daily living or a combination of these (Effing et al. 2009; Monninkhof et al. 2003).

Programs should include the following elements (Alison et al. 2009):

- Minimum duration of 6–8 weeks.
- Minimum of two supervised sessions each week.
- A home exercise program should be concurrent with the supervised program, starting within 1–2 weeks of commencing the supervised program; the home program should be performed 2–3 times per week.
- After completion of the supervised program, patients are advised to continue with home exercise up to 4–5 times per week at home or the gymnasium, indefinitely.
- Home exercises need to be progressive and where possible include exercises that are identical to those performed in the supervised program (Alison et al. 2009).

Effects of pulmonary rehabilitation on health status in patients with COPD

Pulmonary rehabilitation has a wide range of beneficial effects in people with COPD (Dunne et al. 2012; Puhan et al. 2011).

Exercise-based pulmonary rehabilitation in patients with COPD is effective in reducing shortness of breath (dyspnoea) and fatigue, and in improving emotional function and control of the disease (Lacasse et al. 2006). When instituted after a hospital admission, it also reduces the risk of re-hospitalisation and death, and improves quality of life (Puhan et al. 2011). These benefits are mainly attributed to the exercise component of the programs.

The effectiveness of education and psychosocial support as a part of these programs is less well established (Lacasse et al. 2006). However, it has been found that self-management education is associated with positive outcomes such as a reduction in hospital admissions, with no apparent detrimental effects (Effing et al. 2009).

Access to pulmonary rehabilitation in Australia

Available data suggest that access to pulmonary rehabilitation programs in Australia is limited. In 2007, there were 131 pulmonary rehabilitation programs around Australia (ALF 2007). Of those, 80% had a waiting list and in more than half (51%) the waiting period until the start of the next program was greater than four weeks. The poor accessibility was highlighted in a survey of 38 hospitals in New South Wales in 2007. This survey (NSW Agency for Clinical Innovation 2010) found:

- only 5–10% of patients with moderate to severe COPD had accessed pulmonary rehabilitation services
- over three-quarters of pulmonary rehabilitation programs had a waiting period greater than 4 weeks and 37% had a waiting period of greater than 2 months
- fewer than half of the programs had capacity to provide pulmonary rehabilitation services for more than 100 patients per year
- a large proportion of programs did not accept referrals from GPs, allied health or nursing professionals
- 60% of programs could not offer longer-term maintenance exercise programs or follow-up assessment or care for patients who had completed the initial program.

An evaluation of the Lung Foundation Australia's *Breathe Easy Walk Easy* program found that poor access and barriers to participation remain for clients in remote settings and for Indigenous Australians with COPD (Johnston et al. 2010).

Based on this preliminary evidence from the survey and evaluation outlined above, it appears that many, and possibly the majority, of patients with COPD who could benefit from pulmonary rehabilitation, do not receive this service. The reasons include availability of local programs, transport, waiting periods, referral patterns and practitioner and patient choice.

Estimating the extent of this under-utilisation, the associated potential for health gain, and barriers to access may allow policy makers to define options for interventions to improve access.

What is long-term home oxygen therapy (LTOT)?

Long-term oxygen therapy (LTOT) refers to the provision of supplemental oxygen therapy for 15 to 24 hours per day, at home, over a prolonged period for people with chronic respiratory disease who have persistently low levels of oxygen in their blood (hypoxaemia) (Abramson et al. 2013).

The level of oxygen in the blood is usually measured by performing a special blood test (arterial blood gases) to measure the partial pressure of oxygen in the arterial blood (p_aO_2). Patients with COPD who have p_aO_2 less than 55 mm Hg (or less than 60 mm Hg with evidence of certain other complications) are considered hypoxaemic and, therefore, likely to benefit from LTOT (McDonald et al. 2005).

Domiciliary oxygen therapy is the inclusive term used to refer to any oxygen therapy used in the home (including LTOT) generally to treat episodic hypoxaemia. In contrast with evidence supporting LTOT, use of oxygen for treating episodic hypoxaemia has limited supporting evidence and is not generally subsidised.

In Australia, this therapy is predominantly delivered using an oxygen concentrator – an electric-powered device that increases the concentration of oxygen of air by extracting nitrogen. This oxygen-enriched air is usually administered to the patient by tubing connected to nasal prongs (short tubes) or, less commonly, by face mask and occasionally by intratracheal cannula (McDonald et al. 2005; Serginson et al. 2009).

Effects of LTOT on health status in patients with COPD

LTOT improves survival and quality of life in people with hypoxaemia due to COPD (Dunne et al. 2012; McDonald et al. 2005; Nocturnal Oxygen Therapy Trial Group 1980). The principles underlying its use are summarised in Box 1.2.

It is important to note that in patients with COPD who do not have low levels of oxygen in their blood, LTOT does not have beneficial effects (and does not relieve breathlessness).

Box 1.2: What is considered good management for patients with COPD complicated by hypoxaemia?

This summary is of key elements from the adult domiciliary oxygen therapy position statement from the Thoracic Society of Australia and New Zealand, 2005:

- Ensure that patients meet the criteria for LTOT as defined in the guidelines.
- Provide LTOT, defined as 15 hours or more per day.
- Review arterial blood gases between one and three months after commencing oxygen therapy.
- Review the use of oxygen therapy after one year (McDonald et al. 2005).

Access to LTOT in Australia

Although the eligibility criteria for LTOT vary between jurisdictions (Serginson et al. 2009), all are closely based on the Thoracic Society of Australia and New Zealand's clinical guidelines (McDonald et al. 2005). They all require evidence of hypoxaemia during a period of clinical stability, and prescription by a respiratory physician (or other nominated specialist).

The use of LTOT varies within Australia, from 44 per 100,000 persons in the Northern Territory to 133 per 100,000 persons in Tasmania. The explanation for these differences is currently unknown (Serginson et al. 2009).

Most states and territories and the Australian Government provide eligible patients with subsidised (or free) LTOT equipment through various medical aids subsidy schemes. Based on one study, the estimated total cost of LTOT funded by individual states and territories in 2004–05 varied between \$1,014 and \$2,574 per patient per prescribed year (Serginson et al. 2009).

The Australian Government funded domiciliary oxygen therapy (which includes short-term oxygen and LTOT) at a cost of over \$31 million a year in 2004–05 for 20,127 patients (includes 2001 data for Western Australia and 2003–04 data for Victoria). This cost excludes administrative and clinical assessment costs (Serginson et al. 2009).

The way LTOT services are organised, funded and delivered varies widely amongst states, territories and regional health authorities. The uptake of LTOT also varies widely across Australia and there are no data that allow assessment of the appropriateness of use, the barriers to uptake, and the outcomes. This gap in knowledge has led to calls by the Lung Foundation Australia, *Medical Journal of Australia* and the Medical Aids Subsidy Scheme of Queensland for the development of a national register for LTOT (Abramson et al. 2013; Serginson et al. 2009).

Purpose and scope of this report

In summary, there is strong evidence that both pulmonary rehabilitation and LTOT are effective interventions in selected patients with COPD. There is some evidence suggesting that these interventions are under-utilised and hence optimal outcomes are not being achieved. The full extent of service provision, utilisation and under-utilisation is unknown as there are no national data.

The purpose of this report is to:

- describe the rationale for developing a monitoring approach for the use of pulmonary rehabilitation and LTOT in patients with COPD
- develop the monitoring approach
- describe the data sources proposed for use within the monitoring approach.

This report presents potentially measurable indicators of the effectiveness of service provision in relation to pulmonary rehabilitation and LTOT for patients with COPD. For each suggested indicator, it outlines the rationale, the proposed source of data, and how it would be measured. It also proposes and justifies benchmarks against which the effectiveness of service provision would be assessed.

2. Developing a monitoring approach for pulmonary rehabilitation

The following indicators for access and utilisation of pulmonary rehabilitation are proposed for further consideration.

Chapter 3 describes existing or potential data sources that could serve as sources of information for these indicators. It presents a summary of the proposed indicators against possible data sources in Table 3.1. It is important to note that, for some of these indicators, no suitable data sources are available at present.

Proposed indicators for monitoring pulmonary rehabilitation: access indicators

Pulmonary rehabilitation indicator 1: proportion of Local Hospital Networks that offer pulmonary rehabilitation services

Description

Numerator: Number of Local Hospital Networks (LHNs) that offer pulmonary rehabilitation services at one or more of their facilities.

Denominator: Number of Local Hospital Networks.

Rationale

As reported in the preceding chapter, access by patients with COPD to pulmonary rehabilitation services in Australia appears to be limited. The first step in ascertaining the extent of this problem is to quantify the number of services available. Pulmonary rehabilitation is often offered as a hospital outpatient service. Therefore, many pulmonary rehabilitation services will be captured in this indicator.

Interpretation

Each Local Hospital Network (LHN) consists of small groups of local hospitals, or an individual hospital, linking services within a region or through specialist networks across a state or territory. The aim of LHNs is to improve access to health care that is well coordinated, and that promotes efficient use of resources (DoHA 2011a). Australia has 137 LHNs, each run locally, funded nationally and accountable to national standards.

Pulmonary rehabilitation forms part of the outpatient services that may be provided by LHNs. Ideally, all LHNs should offer pulmonary rehabilitation unless the service is adequately provided by other agencies for patients within the network. Therefore, the benchmark for this indicator should be near 100%.

Inability to achieve this benchmark may indicate:

- lack of funding for the service
- lack of adequately trained staff
- different prioritisation of resources

- the availability of adequate resources in nearby areas
- incomplete capture of all relevant services.

Even if 100% coverage is achieved, access by patients may be substantially limited by distance, given the large areas covered by some Local Hospital Networks.

Recommended data sources

- the Lung Foundation Australia national database of pulmonary rehabilitation programs
- the Local Hospital Network Directory.

Pulmonary rehabilitation indicator 2: proportion of Medicare Locals that have pulmonary rehabilitation services available within their area

Description

Numerator: Number of Medicare Locals that have pulmonary rehabilitation services available within their area.

Denominator: Number of Medicare Locals.

Rationale

This indicator would provide information regarding the number of Medicare Locals that have pulmonary rehabilitation services available within their boundaries. It would include both public and private hospital-based and community-based rehabilitation clinics.

This would be a useful companion indicator to the related Local Hospital Network indicator, given that the boundaries of the two entities do not always align and depending on whether the purpose of the indicator was to describe access within Medicare Local or Local Hospital Network boundaries.

Interpretation

Medicare Locals were created in 2011 to plan and fund extra health services across Australia. Sixty-one Medicare Locals were created to ensure decisions about health services could be made by local communities in line with local needs (DoHA 2011b). Medicare Locals are primary health care organisations established to coordinate primary health care delivery. They address local health care needs and service gaps.

The benchmark for this indicator is 100%.

Inability to achieve this benchmark may indicate:

- lack of funding for the service
- lack of adequately trained staff
- different prioritisation of resources
- the availability, e.g. in urban regions, of adequate resources in neighbouring areas
- incomplete capture of all relevant services.

Even if 100% coverage is achieved by this indicator, access by patients may be substantially limited by distance, given the large areas covered by some Medicare Locals.

Recommended data sources

- the National Health Services Directory (NHSD) for the Medicare Locals (this will contain information on allied health services provided in each Medicare Local)
- the Lung Foundation Australia's national database of pulmonary rehabilitation programs (see Chapter 3, Existing data sources)
- publicly available nationwide list of Medicare Locals.

Pulmonary rehabilitation indicator 3: number of places available in pulmonary rehabilitation services per year per 100,000 population

Description

Numerator: Number of patient positions available per year in current pulmonary rehabilitation services.

Denominator: Total Australian population ('100,000s).

Rationale

As reported in the preceding chapter, fewer than half the programs surveyed in New South Wales in 2010 were able to admit more than 100 people per year into pulmonary rehabilitation programs. Most programs had waiting lists, and for 37% of programs the waiting time was over 12 months (NSW Agency for Clinical Innovation 2010). Hence, information on the number of services available does not necessarily indicate the adequacy of service supply. It is also necessary to assess the adequacy of supply of actual places within programs.

Interpretation

There is no consensus recommendation on a benchmark for this indicator. More work, including descriptive epidemiological studies, is needed to establish this benchmark. However, the existence of long waiting lists at many sites in a New South Wales Agency for Clinical Innovation 2010 survey indicates that places for pulmonary rehabilitation are underprovided at present, at least in that state.

Analysis of this indicator separately by places for new attendees and places for people who are attending maintenance or refresher programs would add to its value for service planning.

Recommended data sources

- no existing data source (see Chapter 3 for future data development options).

Pulmonary rehabilitation indicator 4: number of places available in pulmonary rehabilitation services per year per 1,000 people with COPD

Description

Numerator: Number of patient positions available per year in current pulmonary rehabilitation services.

Denominator: Number of people with COPD ('1,000s) aged 40 and over.

Rationale

This indicator provides an alternative way of interpreting data about service availability, in this case relative to potential demand.

Interpretation

There is no consensus recommendation on a benchmark for this indicator. More work is needed to establish this.

Recommended data sources

- no existing data source (see Chapter 3 for data development options).

Proposed indicators for monitoring pulmonary rehabilitation: utilisation indicators

Pulmonary rehabilitation indicator 5: proportion of people with symptomatic COPD who have ever attended a pulmonary rehabilitation program

Description

Numerator: Number of people with symptomatic COPD (more specifically, a diagnosis of COPD and shortness of breath due to COPD) who have participated in a pulmonary rehabilitation program.

Denominator: Number of people with symptomatic COPD.

Rationale

Although the strongest evidence for the effectiveness of pulmonary rehabilitation is for moderate to severe COPD, anyone who has COPD and is short of breath on exertion could potentially benefit from participating in a pulmonary rehabilitation program.

Interpretation

The benchmark for this indicator is 100%.

Inability to achieve this benchmark may indicate:

- lack of access to pulmonary rehabilitation services (see Chapter 2 'access indicators')
- failure to diagnose COPD in symptomatic patients with the disease due to people with COPD not presenting to doctors or doctors failing to diagnose COPD in people with symptoms who present to them
- failure of doctors to refer patients with symptomatic COPD to pulmonary rehabilitation programs
- patients' decision not to accept referral to a pulmonary rehabilitation program
- incomplete capture of all relevant people attending a program.

Recommended data sources

- no existing data source for number of people who have attended pulmonary rehabilitation services (see Chapter 3 for data development options).

Pulmonary rehabilitation indicator 6: proportion of people with COPD enrolling in a pulmonary rehabilitation program in the last 12 months who completed the program

Description

Numerator: Number of people with COPD who commenced a supervised pulmonary rehabilitation program within the last 12 months and who completed the program.

Denominator: Number of people with COPD who commenced a supervised pulmonary rehabilitation program over the last 12 months.

Rationale

This indicator will help assess the proportion of people commencing a supervised pulmonary rehabilitation program who participated for a time expected to achieve clinical benefit. For this purpose, a standardised definition of completion of a pulmonary rehabilitation program needs to be developed, based on evidence about effectiveness and feasibility for completion by people with COPD.

The Australian Pulmonary Rehabilitation Toolkit recommends that pulmonary rehabilitation programs should include a minimum of two supervised sessions per week, for at least six weeks (Alison et al. 2009). There is evidence, however, that longer programs may produce greater benefits (ACAM 2003; Ries et al. 2007). Currently, pulmonary rehabilitation programs vary in length and number of supervised sessions per week and the definition of completion of a program may vary across different programs. However, program length and overall attendance can be measured. An Australian survey of 147 pulmonary rehabilitation programs found that 65% ran for 8 weeks or longer (Johnston et al. 2011).

Interpretation

The benchmark for this indicator is 100%.

Inability to achieve this benchmark may indicate:

- Service-related factors such as poor access to transport or other costs incurred due to attendance
- Patient-related factors including perceived lack of benefit, exacerbations of COPD not requiring hospitalisation, carer role for others in the family, co-morbid conditions that limit mobility, such as arthritis, or an intervening admission to hospital
- incomplete capture of all relevant people attending a program.

Recommended data sources

- no existing data source. If a suitable source were identified, further work would be needed to define an agreed period in which a pulmonary rehabilitation program should reasonably be expected to be completed (see Chapter 3 for data development options).

Pulmonary rehabilitation indicator 7: proportion of people discharged from hospital after an exacerbation of COPD within the last 12 months, who have not completed pulmonary rehabilitation within the previous 12 months, and who are provided with a referral to pulmonary rehabilitation upon discharge

Description

Numerator: Number of people discharged from hospital after an exacerbation of COPD within the last 12 months, who have not completed pulmonary rehabilitation within the previous 12 months, and who are provided with a referral for pulmonary rehabilitation.

Denominator: Number of people discharged from hospital after an exacerbation of COPD within the last 12 months.

Rationale

Exacerbations and hospitalisations are common in people with moderate to severe COPD, and they represent a substantial burden within the health care system. The main cost drivers for COPD care are Emergency Department visits and hospital admissions for acute exacerbations (Puhan et al. 2011).

Pulmonary rehabilitation after an acute exacerbation of COPD reduces the risk of subsequent hospital admission or death (Puhan et al. 2011). Thus all patients with COPD who are hospitalised for an acute exacerbation will potentially benefit from a pulmonary rehabilitation program.

Interpretation

Further work is needed to identify a suitable benchmark for this indicator. Although existing evidence indicates that a referral should be provided for all patients discharged after a hospitalisation with an acute exacerbation of COPD who have not previously completed a pulmonary rehabilitation program, consensus needs to be established about whether to refer patients who have already participated in a pulmonary rehabilitation program. For example, a new referral may be considered if a patient has not attended a pulmonary rehabilitation program within the previous 12 months.

There may be some difficulty in obtaining data for this indicator, depending on the way that referrals to pulmonary rehabilitation are provided within each hospital, e.g. whether the referral is given to the patient or to the pulmonary rehabilitation department; and also depending on whether such referrals are routinely documented within the hospital system.

Recommended data sources

- no existing data source (see Chapter 3 for data development options).

High-risk populations

For reporting purposes, the proposed utilisation indicators would ideally be presented by:

- broad age group: all ages, 50–64, 65–74 and 75 and over
- sex
- Indigenous status

- a location-based measure of socio-economic disadvantage– for example, the Australian Bureau of Statistics Socio-Economic Indexes for Areas (SEIFA) Index of Relative Socio-Economic Disadvantage (IRSD)
- remoteness areas (for example, Major cities, Inner/Outer regional, Remote and Very remote areas).

These factors identify high-risk populations who may have poor access to, or under-utilisation of, pulmonary rehabilitation.

3. Data sources for monitoring pulmonary rehabilitation

Existing data sources

AIHW National Hospital Morbidity Database

The AIHW National Hospital Morbidity Database (NHMD) is an administrative data set maintained by the AIHW. It is a collection of information about care provided to patients admitted to Australian public and private hospitals. The database contains information on diagnosis, demographic characteristics, procedures performed and duration-of-stay for episodes of care for patients admitted to hospital (AIHW 2012b).

Using the NHMD to inform the monitoring approach

The database could be used to inform the denominator for the indicator measuring the proportion of people discharged from hospital after an exacerbation of COPD who have a referral to pulmonary rehabilitation. In using these data for this purpose, it would be important to exclude hospital separations due to death, transfer to another hospital or change in the type of care.

A limitation in using these data for the monitoring approach is that the same person could be admitted to hospital more than once in one year, with each episode of care counting towards the total number of hospital separations. However, individual patients are only likely to be referred to pulmonary rehabilitation on one occasion per year (at most). This would result in over-estimation of the denominator.

Medicare Locals and the National Health Service Directory

A key role of Medicare Locals is to improve access to primary health care services for local communities by:

- maintaining up-to-date local service directories to make it easier for patients to access the services they need, by linking local GPs, nursing and other health professionals, hospitals and aged care, Aboriginal and Torres Strait Islander health organisations
- identifying service gaps, where local communities are missing out on services they might need
- co-ordinating services (DoHA 2011b).

Consistent with this role, Medicare Locals each have their own website and are encouraged to add a link on their site to the National Health Service Directory (NHSD). Medicare Locals and other authorised organisations will help maintain information in their respective areas and may add further information as national service and practitioner datasets expand (National Health Call Centre Network 2012).

The directory is a newly developed, comprehensive online registry of medical services nationwide. It is funded by all Australian governments and will integrate with Medicare Locals (National Health Call Centre Network 2012).

The directory is based on the existing Victorian model, the Victorian Human Services Directory (VicHSD) (National Health Call Centre Network 2012). An up-to-date register of

health, social and disability services in Victoria, VicHSD is designed to help health practitioners find services for their patients. An accompanying version for consumers is also available through the Better Health Channel (Better Health Channel 2012). VicHSD provides information about a diverse range of services including general practice, hospital and pharmacy. It also includes information about pulmonary rehabilitation programs (Department of Human Services 2012). It is planned to expand it in 2013 to provide information on allied health services (National Health Call Centre Network 2012). Unlike data from Local Hospital Networks, the NHSD will include both hospital-based and privately-run allied health services (National Health Call Centre Network 2012).

Using the NHSD to inform the monitoring approach

The directory of services within each network could be used to determine the number of pulmonary rehabilitation services within each Medicare Local and Local Hospital Network. The validity of these data will depend on allied health providers uploading their service details to the Medicare Local or NHSD site.

Lung Foundation Australia's National Database of Pulmonary Rehabilitation Programs

The Lung Foundation Australia (LFA), formerly the Australian Lung Foundation (ALF), provides fundraising, education, advocacy and support relating to COPD and other lung diseases within the Australian community. In 2009, the foundation, together with the Australian Physiotherapy Association, developed a pulmonary rehabilitation toolkit, and they have been actively involved in promoting pulmonary rehabilitation in Australia (Alison et al. 2009).

The foundation manages the National Database of Pulmonary Rehabilitation Programs, the most comprehensive register of pulmonary rehabilitation providers in Australia. The purpose of this register is to identify the location of pulmonary rehabilitation services for patients and referring doctors. The list is generated from details supplied by pulmonary rehabilitation providers but there is no obligation on providers to register and an unknown number have not provided their details to the foundation (ALF 2012).

Using the National Database of Pulmonary Rehabilitation Programs to inform the monitoring approach

The database could be used to gather data needed to inform the utilisation indicators. For example, it may be possible to collect data for a specified period on the number of:

- people with COPD who attended a pulmonary rehabilitation program
- people with COPD who complete a program
- places available in each program.

The database has been used previously to obtain information from pulmonary rehabilitation providers. In 2007, a survey of providers registered with the database collected data on the number of programs offered within a 12 month period, program attendance, number of participants in each course, and barriers to running a pulmonary rehabilitation program (ALF 2007). A survey in 2011 sought information on the structure and content of pulmonary rehabilitation programs in Australia. This national survey achieved a response rate of 83%, with responses from all states and territories and every geographical region (Johnston et al. 2011).

Australian Burden of Obstructive Lung Disease Study

The Australian Burden of Obstructive Lung Disease (BOLD) study measured the prevalence of COPD in Australia, using objective criteria based on lung function (Toelle et al. 2013). BOLD Australia studied 3,357 people aged 40 and over, living in 6 Australian regions.

Using Australian BOLD data to inform the monitoring approach

The prevalence of COPD, defined on internationally-agreed lung function criteria alone, was estimated to be 7.5% (Toelle et al. 2013). The study also measured the proportion of people reporting breathlessness on exertion. Taken together, these data could be used to determine the number of people with COPD who could potentially benefit from pulmonary rehabilitation programs.

Options for future data development

Population health surveys

Population health surveys, including the Australian Bureau of Statistics' Australian Health Survey and the state and territory population health surveys, collect information on reported diagnoses of COPD. However, self-reported diagnosis of COPD lack validity as an indicator of objectively confirmed COPD (Walters et al. 2011). Hence, it is unlikely that population surveys, without objective measures, will be useful for informing these indicators.

Pulmonary rehabilitation registry

A national repository of data on pulmonary rehabilitation programs could be established. This would be most feasible if it was limited to aggregated, de-identified data provided annually by an agreed set of providers of pulmonary rehabilitation services that meet defined criteria (as outlined in Chapter 1). An incentive or compensation for providing data may be required. The steps in establishing a data repository such as this would be:

- establishment of governance arrangements
- agreement on a national minimum dataset
- provision of tools for acquiring the data locally and for uploading it in an aggregated format
- agreement on a reporting format.

Data from this repository could be used to inform both access and utilisation indicators.

Improve national non-admitted patient data collections

Currently, public reporting of non-admitted patient data (also known as outpatient care data) is limited to AIHW reporting using the National Public Hospital Establishments Database and the National Outpatient Care Database (NOCD). There may be opportunities to refine the classification against which these services are collated and reported to include a specific clinic type for pulmonary rehabilitation or more detail on patient diagnosis. This improved data would inform both access and utilisation indicators.

More specifically, the current NOCD is compiled in accordance with specifications in the Outpatient Care National Minimum Dataset (from 2007–08) (AIHW 2013a). Selected hospitals throughout Australia provide records to the NOCD via state/territory health

authorities. These data provide counts of individual occasions of service and group services for 24 types of outpatient services (known as 'clinic types' for the purposes of the collection).

In terms of describing access to and utilisation of pulmonary rehabilitation services, the NOCD has several limitations including:

- Limited coverage of Australian hospitals— the agreed scope of the collection covers principal referral and specialist women's and children's hospitals (Peer Group A hospitals) or large hospitals (Peer Group B hospitals). In 2011–12 this meant that the NOCD covered about 79% of all individual occasions of service and 78% of group sessions delivered by public hospitals. It is not currently possible to estimate how these coverage issues would apply in the specific case of pulmonary rehabilitation clinics.
- The data are counts of occasions of service, not persons, and a person may have multiple occasions of service, at a variety of outpatient clinics or departments reported in a reference year.
- States and territories may differ in the extent to which outpatient services are provided in non-hospital settings (such as community health services) that fall outside the scope of the NOCD (AIHW 2013b).

The 'clinic type' classification in the NOCD does not include a specific clinic type for pulmonary rehabilitation. Therefore the NOCD cannot currently be used within the proposed monitoring approach.

The AIHW will be compiling national outpatient care data from 2013-14 onward according to the Non-admitted patient care aggregate NMDS. This collection expands the clinic types from 24 (in the existing NOCD) to 107 (according to the Tier 2 Non-Admitted Services classification (version 2.0)). This will not address all of the above limitations, including that the enhanced classification does not include a relevant clinic type for pulmonary rehabilitation, nor require information about the diagnosis of the patient (which could be useful if a more generic rehabilitation clinic type were available).

It is, however, possible that more detailed information on non-admitted patient hospital care may become available in future due to various developments in relation to these data. For example, a Non-Admitted Patient Dataset Specification (NAP DSS) was agreed by all states and territories in 2011 to guide collection of more detailed information from 2012–13. Although this collection is not mandatory for jurisdictions and is not currently collated nationally for public reporting purposes, it lays the groundwork for collating more detailed standardised outpatient care information for public reporting in future.

Work is also underway by the Independent Hospital Pricing Authority to improve the classification of subacute care services (which include rehabilitation services) (see, for example, AIHW 2013c). Although this work has focused to date on admitted patient care, it could possibly be applied in non-admitted patient settings.

Many of these developments are being driven by the need for enhanced information to support the introduction of Activity Based Funding, which aims to create a more transparent system of delivery of services and funding for public hospitals in Australia (IHPA 2011). The Independent Hospital Pricing Authority (IHPA) currently collates regular state/territory data according to the Non-Admitted Patient Activity Based Funding Dataset Specification as part of its role in implementing Activity Based Funding with respect to these services (IHPA 2013). Although this information is not provided for public reporting purposes, it is driving improvements in the quantity and quality of information collected about non-admitted patient services in Australia and could be an avenue to pursue future improvements in

information about access to and utilisation of pulmonary rehabilitation by people with asthma and COPD.

Table 3.1: Summary of pulmonary rehabilitation indicators with recommended data sources to inform those indicators

Indicator	Description	Existing data sources	Evaluation of data sources
1. Proportion of Local Hospital Networks that offer pulmonary rehabilitation services	Numerator: The Lung Foundation Australia national database of pulmonary rehabilitation programs Denominator: Local Hospital Network Directory	The Lung Foundation Australia national database of pulmonary rehabilitation programs Local Hospital Network Directory	National database for pulmonary rehabilitation programs is mapped according to LHN by postcode or suburb
2. Proportion of Medicare Locals that have pulmonary rehabilitation services available within their area	Numerator: The National Health Services Directory for the Medicare Locals or the Lung Foundation Australia national database of pulmonary rehabilitation programs Denominator: List of Medicare Locals nationwide	The National Health Services Directory for Medicare Locals or the Lung Foundation Australia national database of pulmonary rehabilitation programs List of Medicare Locals nationwide	National database for pulmonary rehabilitation programs is mapped according to Medicare Local by postcode or suburb
3. Number of places available in pulmonary rehabilitation services per year per 100,000 population	Numerator: Number of patient positions available per year in current pulmonary rehabilitation services Denominator: Total Australian population ('100,000s)	No existing data sources Australian Bureau of Statistics (ABS) census 2011	Future pulmonary rehabilitation surveys could include a question on the capacity for intake per year
4. Number of places available in pulmonary rehabilitation services per year per 1,000 people with COPD	Numerator: Number of patient positions available for intake per year in current pulmonary rehabilitation services Denominator: Number of people with COPD ('1000s)	No existing data sources Burden of Obstructive Lung Diseases, Australia 2013	Future pulmonary rehabilitation surveys could include a question on the capacity for intake per year
5. Proportion of people with symptomatic COPD who have ever attended a pulmonary rehabilitation program	Numerator: Number of people with symptomatic COPD who have ever participated in a pulmonary rehabilitation program Denominator: Number of people with symptomatic COPD	No existing data sources Burden of Obstructive Lung Diseases, Australia 2013	Future pulmonary rehabilitation surveys could include a question on the diagnosis of patients in the program
6. Proportion of people with COPD enrolling in a pulmonary rehabilitation program in the last 12 months who completed the program	Numerator: Number of people with COPD who commenced a defined pulmonary rehabilitation program within the last 12 months, who completed it within 6 months Denominator: Number of people with COPD who commenced a pulmonary rehabilitation program within the last 12 months	No existing data sources	Increase the level of detail in non-admitted patient data collections to include pulmonary rehabilitation as a sub-type of allied health services
7. Proportion of people discharged from hospital after an exacerbation of COPD within the last 12 months, who have not completed pulmonary rehabilitation within the previous 12 months, and who are provided with a referral to pulmonary rehabilitation upon discharge	Numerator: Number of people discharged from hospital after an exacerbation of COPD within the last 12 months, who have not completed pulmonary rehabilitation within the previous 12 months, and who are provided with a referral for pulmonary rehabilitation Denominator: Number of people discharged from hospital after an exacerbation of COPD within the last 12 months	National Hospital Morbidity Database	National Hospital Morbidity Database would need to be modified to include information about referral to pulmonary rehabilitation

4. Developing a monitoring approach for long-term oxygen therapy

The following indicators for access and utilisation of long-term oxygen therapy are proposed for further consideration.

In Chapter 5 we identify the range of data sources that have been evaluated as potential sources of information for these indicators. We also summarise the proposed long-term oxygen therapy indicators against recommended data sources in Table 5.2. In presenting these indicators, it is important to note that there may not be a current data source available to inform the indicator.

Proposed indicators for monitoring long-term oxygen therapy: access indicators

LTOT indicator 1: proportion of Local Hospital Networks that offer LTOT services

Description

Numerator: Number of Local Hospital Networks (LHNs) that offer LTOT services at one or more of their facilities. LTOT services include clinical services for assessment and prescription of LTOT and also supply of subsidised LTOT equipment.

Denominator: Number of LHNs.

Rationale

Hospital doctors often arrange referral of eligible patients for LTOT at the time of hospital discharge. It is important that patients with COPD and hypoxaemia in all LHNs have affordable and equitable access to LTOT.

Interpretation

Each LHN consists of small groups of local hospitals, or an individual hospital, linking services within a region or through specialist networks across a state or territory. The aim of LHNs is to improve access to health care that is well coordinated, and that promotes efficient use of resources (DoHA 2011a). Each of the LHNs is run locally, funded nationally and accountable to national standards; 137 have been agreed upon by all states and territories.

The benchmark for this indicator should be close to 100%. All LHNs should offer LTOT except if the service is adequately provided by other agencies for patients within the network.

Inability to achieve this benchmark may indicate:

- inadequate provision of this service
- the availability of adequate resources in nearby areas (mainly applies to urban areas)
- incomplete capture of all relevant services.

Even if 100% coverage is achieved, access by patients may be substantially limited by distance, given the large areas covered by some LHN.

Recommended data sources

- administrative data associated with State and Territory and National Funding for LTOT and their LTOT suppliers and LHN information from the National Health Services Directory (refer to Chapter 3, 'Existing data sources').

LTOT indicator 2: Proportion of Medicare Locals that have LTOT services available within their area

Description

Numerator: Number of Medicare Locals that have LTOT services available within their area. LTOT services include clinical services for assessment and prescription of LTOT and also supply of subsidised LTOT equipment.

Denominator: Number of Medicare Locals.

Rationale

This indicator would provide information regarding the number of Medicare Locals that have LTOT services available within their boundaries. It would include both hospital-based and privately run specialist and general practice clinics that may provide LTOT services. It is important that patients with COPD and hypoxaemia in all Medicare Local areas have affordable and equitable access to LTOT.

This would be a useful companion indicator to the related Local Hospital Network indicator, given that the boundaries of the two entities do not always align and depending on whether the purpose of the indicator was to describe access within Medicare Local or Local Hospital Network boundaries.

Interpretation

Medicare Locals were created in 2011 to plan and fund extra health services in communities across Australia. Sixty-one Medicare Locals were created to ensure decisions about health services could be made by local communities in line with local needs (DoHA 2011b). Medicare Locals are primary health care organisations established to coordinate primary health care delivery. They address local health care needs and service gaps.

The benchmark for this indicator is 100%.

Inability to achieve this benchmark may indicate:

- inadequate provision of this service
- the availability of adequate resources in nearby areas (mainly applies to urban areas)
- incomplete capture of all relevant services.

Even if 100% coverage is achieved, access by patients may be substantially limited by distance, given the large areas covered by some Medicare Locals.

Recommended data sources

- State and Territory and National Funding for LTOT and their LTOT suppliers and Medicare Local nationwide list.

Proposed indicators for monitoring long-term oxygen therapy: utilisation indicators

LTOT indicator 3: proportion of people with COPD and hypoxaemia who are currently using LTOT

Description

Numerator: Number of people with COPD and hypoxaemia, defined according to TSANZ guidelines (McDonald et al. 2005), who are using LTOT as a part of their management.

Denominator: Number of people with COPD and hypoxaemia (defined according to TSANZ guidelines) who are non-smokers.

Rationale

Use of LTOT is associated with improved survival and quality of life in patients with COPD and hypoxaemia (see Chapter 1, 'Effects of LTOT on health status in patients with COPD') and is therefore recommended for all such patients who are not currently smoking (McDonald et al. 2005; Abramson et al. 2013).

Interpretation

The benchmark for this indicator is 100%.

Inability to achieve this benchmark may be due to any of the following causes:

- doctors' failure to diagnose COPD in people who have this condition and also have hypoxaemia
- doctors' failure to identify hypoxaemia in people with COPD and hypoxaemia
- respiratory physicians' failure to consider LTOT for patients who are diagnosed with COPD and hypoxaemia and who are non-smokers
- refusal by patients to accept a recommended prescription for LTOT from a respiratory physician
- failure of the designated subsidy scheme to provide subsidy for the equipment
- failure of the patient to make any co-payment required for the provision or equipment
- patient discontinuing use of the LTOT
- persistent failure of patient to adhere to LTOT for 15 hours or more per day, resulting in withdrawal of service.

Recommended data sources

- State and Territory and National Funding for LTOT.

LTOT indicator 4: proportion of people prescribed LTOT for COPD who are using it 15 hours or more per day

Description

Numerator: Number of people who are using LTOT 15 hours or more per day.

Denominator: Number of people who are using LTOT.

Rationale

Guidelines recommend that LTOT be used for 15 hours or more per day. This recommendation is based on evidence from two randomised controlled trials, which showed that beneficial effects on survival were achieved with this level of usage (Medical Research Council Working Party 1981; Nocturnal Oxygen Therapy Trial Group 1980). It is important to measure the extent to which users are adhering to this recommendation.

Interpretation

The benchmark for this indicator is 100%.

Inability to achieve this benchmark may be due to:

- failure by the prescribing physician or clinical team to provide appropriate education about the use of LTOT
- adverse effects of LTOT (such as drying of nasal mucosa) that mitigate against adherence to therapy
- failure by the patient to adhere to recommended LTOT for other reasons
- incomplete capture of all people receiving LTOT.

Recommended data sources

- State and Territory and National Funding for LTOT.

LTOT indicator 5: proportion of people commenced on LTOT who have a scheduled review within four months of supply

Description

Numerator: Number of people commenced on LTOT who have a review within four months of supply.

Denominator: Number of people commenced on LTOT.

Rationale

The TSANZ position statement in Box 1.2 stipulates that a review of LTOT should occur within one to three months of commencing the therapy. Some jurisdictions require review at different time intervals and some not at all but most have a review within four months of initial supply. The importance of this review is to determine that the hypoxia was not due to the COPD being unstable during initial prescription and also to determine if the treatment has been worthwhile, appropriately applied and utilised, and should be continued or abandoned (McDonald et al. 2005).

Interpretation

The benchmark for this indicator is 100%.

Inability to achieve this benchmark may indicate:

- failure of the treating clinical team to schedule a review
- failure of patient to attend a scheduled review
- incomplete capture of all people receiving LTOT.

Recommended data sources

- State and Territory and National Funding for LTOT.

LTOT indicator 6: proportion of people who are using LTOT and have a scheduled review every 12 months

Description

Numerator: Number of people who have used LTOT for more than 18 months who have a scheduled clinical review within the preceding 12 months.

Denominator: Number of people who have used LTOT for more than 18 months.

Rationale

In Box 1.2 the TSANZ position statement recommends that a person on LTOT should be reviewed annually, or more often according to their clinical situation (McDonald et al. 2005).

Interpretation

The benchmark for this indicator is 100%.

Inability to achieve this benchmark may indicate:

- failure of the treating clinical team to schedule a review
- failure of patient to attend a scheduled review
- incomplete capture of all people receiving LTOT.

Recommended data sources

- State and Territory and National Funding for LTOT.

High-risk populations

The proposed utilisation indicators to identify high-risk populations with poor access to, or under-utilisation of, LTOT would be ideally presented by:

- broad age group: all ages, 50–64, 65–74 and 75 and over
- sex
- Indigenous status
- a location-based measure of socio-economic disadvantage—for example, the Australian Bureau of Statistics Socio-Economic Indexes for Areas (SEIFA) Index of Relative Socio-Economic Disadvantage (IRSD)
- remoteness areas (for example, Major cities, Inner/Outer regional, Remote and Very remote areas).

5. Data sources for monitoring LTOT

Existing data sources

State and Territory and National Funding for LTOT

Several agencies fund and deliver LTOT for eligible patients. In most states and territories, the main funding agency is the jurisdiction's department of health. However, the Department of Veterans Affairs provides LTOT for eligible Australian war veterans and the Department of Health funds it for those in aged care facilities.

Each of these agencies requires a prescription or referral for LTOT from the treating clinician, who is usually a respiratory physician, but in some jurisdictions can be a respiratory Nurse Practitioner or General Practitioner. This referral includes clinical information that is used by the agencies to assess the client's eligibility under funding guidelines. If the client is deemed to be eligible (see Chapter 1, 'Access to LTOT in Australia'), the agency then sends the referral to an oxygen supplier, who delivers the equipment to the client.

Using the State and Territory and National Funding data to inform the monitoring approach

Some of the data used to assess eligibility are recorded by the funding agencies. Potentially, these data could be used to inform the indicators on utilisation of LTOT. However, not all the information on the referral forms is recorded in the database. Furthermore, the available information varies between jurisdictions and agencies. For example, although the majority of funding agencies require regular reviews (initial 1–2 months and annual reviews) of LTOT, they are not consistent nationwide. In addition, given the variability across jurisdictions in the way LTOT services are funded and delivered, it would be necessary to consider all funding data combined to obtain an overall picture of utilisation and access.

Effective use of these referral data for monitoring LTOT utilisation would require agreement on a national minimum dataset. The data elements that are relevant to the proposed indicators for LTOT are listed in Table 5.1, along with information on what is currently recorded in the referral forms and in databases in states/territories and the national Department of Veteran's Affairs data collection.

Oxygen suppliers in Australia

Several companies supply oxygen concentrators and portable oxygen in Australia. They usually have contracts with funding agencies to supply specified clients. Clients may also buy or rent an oxygen concentrator or portable oxygen device directly from a supplier. This is most likely to occur if the funding agency decides that the client is ineligible for funding support on clinical or financial grounds but may also occur when the treating clinician is unaware of the availability of a subsidised program or unable to access it.

Using data from oxygen suppliers to inform monitoring approach

Most oxygen concentrators have an in-built device for recording the number of hours the device has been operating. Many oxygen suppliers record this information which can be fed back to the government funding agencies. Clinicians and agencies use this information to assess the client's adherence with LTOT, but this is not universal. If collected regularly and

consistently, this information could be used to inform the indicator measuring the proportion of people who are using LTOT 15 hours or more per day.

Australian Burden of Obstructive Lung Disease Study

The Australian Burden of Obstructive Lung Disease (BOLD) study (Toelle et al. 2013) measured the prevalence of COPD using objective criteria-based lung function measured in 3,357 people aged 40 and over living in 6 Australian regions.

Using BOLD, Australia to inform the monitoring approach

The prevalence of COPD in Australia was estimated to be 7.5% (Toelle et al. 2013). Further work would be needed to estimate the prevalence of hypoxaemia severe enough to require LTOT among people with COPD. These data are required to estimate the denominator for the indicators of utilisation of LTOT.

Options for data development

Health measurement survey

There are no data on the prevalence of hypoxaemia in people with COPD. The recent BOLD survey has measured the prevalence of COPD, based on measurement of spirometric lung function in a general population sample (Toelle et al. 2013). It may be possible to include measurement of oxygen saturation by pulse oximetry (a cheap non-invasive test) in future similar surveys. It may also be possible to include measurement of spirometric lung function and oxygen saturation in a future national health measurement survey.

These data are required to estimate the denominator for the utilisation indicators.

Population health surveys

Existing population health surveys, including the National Health Survey or the state and territory population health surveys, could be adapted to include questions that identify people who are using LTOT.

These data would be useful for estimating the numerator of the utilisation indicators.

Table 5.1: Summary of data variables recorded by state and territory referral form and database relevant to proposed LTOT indicators

Data variables										Proposed Indicators			
State/Territory referral forms and guidelines and databases	Diagnosis	ABG ^(a) at initial	Prescribed 15 hours or more per day	Type of equipment	Review at 6–8 weeks after supply	ABG ^(a) at 3 month review	Review every 12 months	ABG ^(a) or oximetry at 12 month review	Record of hours of use	People with COPD and hypoxaemia currently using LTOT	Proportion using LTOT 15 hours or more per day	Review at 6–8 weeks	Review every 12 months
Enable NSW													
Referral form	✓	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓
Database	✗	✗	✓	✓	✗	✗	✗	✗	✗	✗	✓	✗	✗
Statewide Equipment Program VIC													
Referral form	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	✓	✓	✓
Database	✓	✗	✓	✓	✗	✗	✓	*	*	✓	✗	✗	✓
Medical Aids Subsidy scheme Qld													
Referral form	✓	✓	✓	✓	✓	✓	✓	n.a.	✓	✓	✓	✓	✓
Database	✓	✗	✓	✓	✓	✗	✓	✗	*	✓	✓	✗	✓
Department of Health WA													
Referral form	✓	✓	✓	✓	✓	✓	✓	✗	✓	✓	✓	✓	✗
Database (Silver Chain)	✗	✗	✗	✓	✓	✗	✓	✗	✗	✗	✗	✗	✗

Table continued

Table 5.1 (continued): Summary of data variables recorded by state and territory referral form and database relevant to proposed LTOT indicators

Data variables										Proposed Indicators			
State/Territory referral forms and guidelines and databases	Diagnosis	ABG ^(a) at initial	Prescribed 15 hours or more per day	Type of equipment	Review at 6–8 weeks ^(a) after supply	ABG ^(b) at 3 month review	Review every 12 months	ABG ^(a) or oximetry at 12 month review	Record of hours of use	People with COPD and hypoxaemia currently using LTOT	Proportion actual use LTOT 15 hours or more / day	Review at 6–8 weeks	Review every 12 months
Department of Health SA													
Referral form	✓	✓	✓	✓	x	x	x	x	x	x	x	x	x
Database	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a
Royal Hobart Hospital, TAS													
Referral form	✓	✓	✓	✓	✓	x	x	x	x	✓	x	✓	x
Database	✓	x	✓	✓	x	x	x	x	x	✓	x	x	x
ACT Domiciliary oxygen respiratory support scheme													
Referral form	✓	✓	✓	✓	x	x	✓	x	x	✓	x	x	✓
Database	✓	x	✓	✓	x	x	✓	x	x	✓	x	x	✓
Disability equipment program NT													
Referral form	✓	✓	✓	✓	✓	x	✓	✓	✓	✓	✓	x	✓
Database	✓	✓	✓	✓	✓	x	✓	✓	x	✓	x	x	✓
DVA													
Referral form	✓	✓	✓	✓	x	x	✓	x	x	✓	x	✓	x
Database	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a	n.a

(a) Queensland conducts a review within 4 months of supply. (b) Arterial blood gases.

Note * indicates that variable is collected elsewhere but not on current database.

Table 5.2: Summary of LTOT indicators with recommended data sources to inform those indicators

Indicator	Description	Existing databases	Evaluation of databases
1. Proportion of Local Hospital Networks that offer LTOT services	Numerator: Number of Local Hospital Networks that offer LTOT services at one or more of their facilities Denominator: Number of Local Hospital Networks	State and Territory and National Funding for LTOT Local Hospital Network Directory database	Identify suppliers in each jurisdiction and map according to LHN by postcode or suburb
2. Proportion of Medicare Locals that have LTOT services available within their area	Numerator: Number of Medicare Locals that have LTOT services available within their area Denominator: Number of Medicare Locals	State and Territory and National Funding for LTOT Medicare Local nationwide list	Identify suppliers in each jurisdiction and map according to Medicare Local by postcode or suburb
3. Proportion of people with COPD and hypoxaemia who are currently using LTOT	Numerator: Number of people with COPD and hypoxaemia who are using LTOT as a part of their management Denominator: Number of people with COPD and hypoxaemia who are non-smokers.	State and Territory and National Funding for LTOT No current data sources	Development of a national minimum dataset to ensure that the data variables Diagnosis and ABG at initial which are present on the referral forms are included in each jurisdiction's database
4. Proportion of people prescribed LTOT for COPD who are using it 15 hours or more per day	Numerator: Number of people who are using LTOT 15 hours or more per day Denominator: Number of people who are using LTOT	State and Territory and National Funding for LTOT State and Territory and National Funding for LTOT	Development of a national minimum dataset to ensure that the data variables Prescribed 15 hours or more per day and Record of hours of use are included in each jurisdiction's database
5. Proportion of people commenced on LTOT who have a scheduled review within four months of supply	Numerator: Number of people commenced on LTOT who have a review within four months of supply Denominator: Number of people commenced on LTOT	State and Territory and National Funding for LTOT State and Territory and National Funding for LTOT	Development of a national minimum dataset to ensure that the data variable Review before 4 months which is present on most referral forms and state/territory guidelines is included in each jurisdiction's database
6. Proportion of people who are using LTOT and have a scheduled review every 12 months	Numerator: Number of people who have used LTOT for more than 18 months who have a scheduled clinical review within the preceding 12 months. Denominator: Number of people who have used LTOT for more than 18 months.	State and Territory and National Funding for LTOT State and Territory and National Funding for LTOT	Development of a national minimum dataset to ensure that the data variable Review every 12 months which is present in most state/territory guidelines is included in each jurisdiction's database

6. Summary and implications for other chronic diseases

There is strong evidence that both pulmonary rehabilitation and LTOT are effective interventions in selected patients with COPD. However, some reports suggest that these interventions are under-utilised and that optimal outcomes are therefore not being achieved. Hence, there is value in monitoring the provision of these therapies.

Since there are no existing national data for these interventions, the full extent of service provision, utilisation and under-utilisation is unknown. This is further complicated by the absence of agreed, standardised definitions of pulmonary rehabilitation and LTOT, and the lack of uniform registration of episodes of provision of these therapies linked to individual patients.

The first step in developing and informing a monitoring approach that could be used to evaluate the effectiveness, efficiency, accessibility and quality of service provision is to decide what is important to monitor. This report has identified and defined several access and utilisation indicators that would be a useful basis for the evaluation of pulmonary rehabilitation services and LTOT therapies.

Recommended pulmonary rehabilitation indicators are:

1. Proportion of Local Hospital Networks that offer pulmonary rehabilitation services
2. Proportion of Medicare Locals that have pulmonary rehabilitation services available within their area
3. Number of places available in pulmonary rehabilitation services per year per 100,000 population
4. Number of places available in pulmonary rehabilitation services per year per 1,000 people with COPD
5. Proportion of people with symptomatic COPD who have ever attended a pulmonary rehabilitation program
6. Proportion of people with COPD enrolling in a pulmonary rehabilitation program in the last 12 months who completed the program
7. Proportion of people discharged from hospital after an exacerbation of COPD within the last 12 months, who have not completed pulmonary rehabilitation within the previous 12 months, and who are provided with a referral to pulmonary rehabilitation upon discharge.

Recommended LTOT indicators are:

1. Proportion of Local Hospital Networks that offer LTOT services
2. Proportion of Medicare Locals that have LTOT services available within their area
3. People with COPD and hypoxaemia who are currently using LTOT
4. Proportion of people prescribed LTOT for COPD who are using it 15 hours or more per day
5. Proportion of people commenced on LTOT who have a scheduled review within four months of supply
6. Proportion of people who are using LTOT and have a scheduled review every 12 months.

Limited data are available to enable the monitoring of these proposed indicators and, hence, evaluate provision of pulmonary rehabilitation and LTOT services in Australia.

Key options for data development

This report has outlined several suggestions for enhancing information about pulmonary rehabilitation and LTOT services. These include:

- enhancing the national admitted patient hospital minimum dataset to incorporate more data variables from referral/discharge forms
- including relevant questions in population health surveys
- mapping suppliers of LTOT and providers of pulmonary rehabilitation programs by Local Hospital Networks or Medicare Local boundaries
- increasing the level of detail in non-admitted hospital patient data collections.

Implications for other chronic diseases

This report has highlighted the importance of two non-inpatient, non-procedural and non-pharmaceutical components of care for patients with COPD: pulmonary rehabilitation and LTOT. The findings may be relevant to understanding the management of other acute and chronic diseases, for example through:

- rehabilitation programs for patients with cardiac, neurological, and musculoskeletal diseases
- providing physical aids for people with neurological and musculoskeletal chronic diseases
- providing dialysis for patients with end-stage renal disease
- psycho-social counselling for people with psychiatric disease
- vaccinating patients with a range of chronic disease.

Effective chronic disease management generally involves coordinated care by health professionals across various hospital and community settings and involving different types of treatment and facilitation of access to a range of aids, equipment and further advice where appropriate. Government and non-government agencies evaluating the provision of care for patients with chronic disease and formulating policy to improve the provision of care for these patients would benefit from improved data about these broad range of services.

Glossary

Aboriginal: A person of Aboriginal descent who identifies as an Aboriginal and is accepted as such by the community in which he or she lives.

Arterial blood gases: A test performed on arterial blood to measure the partial pressures and concentrations of carbon dioxide and oxygen along with the pH and bicarbonate level.

Benchmarking: A continuous process of measuring quality or performance against the highest standards.

Chronic obstructive pulmonary disease (COPD): A preventable and treatable disease with some significant extra-pulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is characterized by airflow limitation that is not fully reversible. The airflow limitation is usually progressive and associated with an abnormal inflammatory response of the lung to noxious particles or gases (GOLD 2013). It may be characterised by emphysema and/or chronic bronchitis. By far the greatest cause is cigarette smoking.

Dyspnoea: breathlessness or shortness of breath

Health survey: A research method in which health information is collected from participants at a point in time. In population health monitoring, this typically involves selecting a representative sample of the population and administering questionnaires to the participants. This can be done in person, over the phone or by post. Some surveys include physiological measurements.

Hypercapnia: Presence of excess carbon dioxide

Hypoxaemic: Deficient oxygenation of the blood (note that the TSANZ guidelines define a level of hypoxaemia that is required to qualify for LTOT (McDonald et al. 2005)

Indicator: A key statistical measure selected to help describe (indicate) a situation concisely, track progress and performance, and act as a guide to decision-making. It may have an indirect meaning as well as a direct one; for example, Australia's overall mortality rate is a direct measure of mortality but is often used as a major indicator of population health.

Indigenous: A person who identifies themselves as an Aboriginal or Torres Strait Islander.

Local Health Network: small groups of local hospitals, or an individual hospital, linking services within a region or through specialist networks across a state or territory. There are 137 Local Hospital Networks in Australia.

Long-term oxygen therapy (LTOT): administration of oxygen as a medical intervention prescribed 15 hours or more per day.

Medicare Local: primary health care organisations in Australia that link local GPs, nursing and other health professionals, hospitals and aged care, Aboriginal and Torres Strait Islander health organisations within 61 defined Medicare Locals.

Oedema: swelling caused by fluid in the body's tissues.

Polycythaemia: a condition in which there are too many red blood cells in the blood circulation.

Pulmonary rehabilitation: A system of care that includes education, exercise training, nutrition counselling and psychosocial support. Exercise training includes aerobic training of

upper and lower limbs and trunk muscles, flexibility and muscle strength as well as teaching breathing control. Education improves the patient's knowledge about breathing and assists smokers to quit and sustain quitting. Patients are trained to optimise activities and nutrition, gain control over anxiety, panic or depression, and use appropriate medications and therapeutic devices effectively (Frith 2008).

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Related publications

The following AIHW publications relating to monitoring chronic respiratory diseases in Australia may also be of interest:

AIHW: Australian Centre for Asthma Monitoring 2011. Asthma in Australia 2011: with a focus chapter on chronic obstructive pulmonary disease. Asthma series no. 4. Cat. no. ACM 22. Canberra: AIHW.

AIHW: Australian Centre for Asthma Monitoring 2009. Refining national asthma indicators: Delphi survey and correlation analysis. Asthma. Cat. no. ACM 15. Canberra: AIHW.

AIHW: Australian Centre for Asthma Monitoring 2007. Australian asthma indicators: five-year review of asthma monitoring in Australia. Cat. no. ACM 12. Canberra: AIHW.

Chronic obstructive pulmonary disease (COPD) is a major cause of death and disability in Australia. While pulmonary rehabilitation and long term oxygen therapy are recommended treatments for COPD, there is currently no national information about the supply and use of these therapies. This report outlines a proposed approach to monitoring access to, and utilisation of, these therapies, by capitalising on existing data sources and identifying data development opportunities.