



Government of **Western Australia**  
Department of **Health**

# Respiratory Health Policy position for the procurement of community based services

V0.2 August 2020

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## Contents

Policy Position Objective	2
Policy Environment and Role of System Manager	2
Background	2
Methodology	3
Key Themes and Findings	3
Lack of access to key services	3
Other services lacking within the system	4
Limited accessible information on respiratory conditions and community-based services	4
Lack of effective collaboration and integration of care	5
Areas of Focus	5
Service Development Areas	6
Identified Areas for Future Focus	7
Next Steps	9
Appendix 1 Summary of Literature Review	10
Respiratory Conditions	10
Priority Populations	13
Appendix 2 Community Based Respiratory Service Mapping in Western Australia	15
Appendix 3 Stakeholders Consulted	20

## Policy Position Objective

The information presented in this document will allow clear alignment of the System Manager's policy position and will take into consideration best practice care standards, high value health care and improved accessibility in future community services procured. The policy position will provide guidance on the commissioning of community-based respiratory health services based on the need of the Western Australian population.

## Policy Environment and Role of System Manager

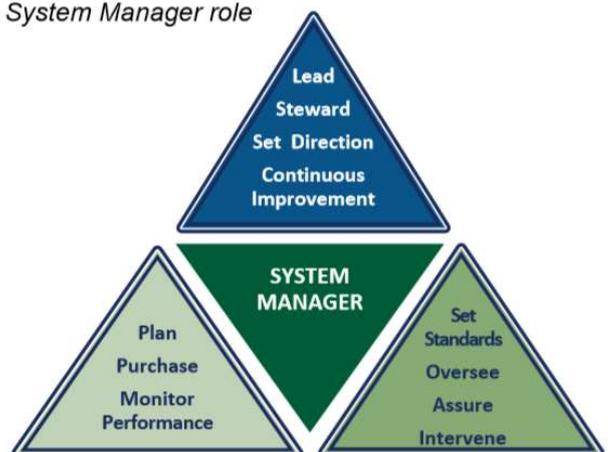
The work undertaken to determine a policy position for the commissioning of community-based respiratory services in Western Australia have taken into consideration the following overarching policies and documents:

- Sustainable Health Review (2019)
- National Strategic Framework for Chronic Conditions
- Delivering Community Services in Partnership Policy (2018)
- Lung Foundation Australia National Strategic Action Plan for Lung Conditions
- WA Aboriginal Health and Wellbeing Framework 2015-2030
- National Asthma Strategy 2018
- WA Health Promotion Strategic Framework 2017-2021
- WA Health Clinical Services Framework 2014-20204
- WA Disability Health Framework 2015-2025

The key functional elements of the System Manager are outlined in Figure 1 below. The System Manager undertakes service planning to forecast demand and the changing needs for health service delivery and inform purchasing and resource allocation.

Through the development of systemwide policy and plans, the System Manager informs purchasing priorities and may identify and recommend system wide service contracts where systemwide application will improve efficiency, effectiveness and access to integrated health and community care<sup>1</sup>.

Figure 1. The System Manager role



## Background

Respiratory health conditions are estimated to affect one in four Australians and contribute to 8% of the total disease burden in Australia. The impact of respiratory health conditions on individuals are significant with treatment often being long term. A review of literature has examined the current state of respiratory health services in Western Australia (Appendix 1) and this has formed the basis for the work undertaken in developing this policy position.

In alignment with the role of the System Manager and the current policy environment, it has been identified that the future commissioning of respiratory health services needs a strong partnership

<sup>1</sup> *The role of an effective System Manager*; Health Reform Fact Sheet. 2016. Department of Health, Western Australia

between service providers and service users to achieve better outcomes for Western Australians with respiratory conditions.

This document summarises the key findings from the work undertaken to develop the policy position. The policy position includes areas of focus for service development, and suggestions for improvement for the design and procurement of community based respiratory services.

## **Methodology**

In May 2020 the Respiratory Health Network (RHN) of the Department of Health (DoH) undertook a review of the existing literature to analyse the community need for respiratory services and identify best practice and key policy requirements. A summary of the literature review and priority populations focused on is outlined in Appendix 1.

Following this work, PricewaterhouseCoopers (PwC) were engaged to consult with stakeholders throughout the WA health system to: map current services; validate the identified health and service needs; identify key gaps in service provision and obtain views on the priorities for service development and improvement.

The work PwC undertook included:

- A rapid desktop review of existing documentation and data
- Mapping of community based respiratory services in Western Australia (see Appendix 2)
- Interviews and workshops with a range of stakeholders in respiratory health (including consumers, carers, service providers, commissioning/peak bodies and clinicians). A list of stakeholders consulted can be found in Appendix 3.
- Co-development of areas of focus for service development and improvement

## **Key Themes and Findings**

Three themes emerged in the current state assessment of community based respiratory health services in Western Australia.

### **Lack of access to key services**

There is a lack of accessibility to a range of services that are critical to the optimisation of diagnosis, treatment and management of chronic respiratory conditions in the community. Principally this is due to a lack of availability of these services (either statewide and/or regions / population groups); however, there are also difficulties accessing existing services (for example due to distance, cost and / or restrictive referral criteria).

Based on the review of literature, the mapping of services and consultees' feedback, the following have been identified as the biggest gaps in availability and/or access to services in meeting health and service needs:

### **Community physiotherapy and pulmonary rehabilitation**

Most pulmonary rehabilitation and general physiotherapy service such as airway clearance education are conducted in a hospital setting, and there is an overall lack of services provided throughout the state, most notably in rural areas – for children and adults. GPs typically do not refer to community services for pulmonary rehabilitation, due to a lack of awareness of services and restrictive referral criteria precluding from them doing so directly. Both the review of literature and stakeholder consultees highlighted the importance of pulmonary rehabilitation to effectively manage a range of respiratory conditions.

## **Lung function testing**

A significant proportion of GP practices currently lack the equipment and/or skills to accurately perform the tests and correctly interpret the results. Significant funding issues also exist, with Medicare rebates not covering the cost of tests. There was near universal consensus from consultees and the review of literature on the importance of increasing and improving the quality of testing.

## **COPD early intervention, diagnosis and management**

There is no tailored approach within the community to support the early intervention, diagnosis and management of people with COPD, despite it accounting for the highest percentage of total disease burden of all respiratory conditions. This includes need for increase uptake of spirometry testing, smoking cessation, access to pulmonary spirometry and education on appropriate use of inhaler therapy.

## **Mental health support services**

There are few mental health services and specialists with sufficient knowledge of how to support people with respiratory conditions, meaning these patients are rarely referred to mental health services. The majority of stakeholders consulted, including consumers, highlighted mental health services as being of paramount importance to people with respiratory conditions; as well as for their carers, parents and families. Investment into co-commissioning for mental health services needs to be explored to better meet the needs of the WA community. Improved integrations and referral pathways to mental health services would be of significant benefit for those people who live with chronic respiratory disease.

## **Other services lacking within the system**

There were a range of other services which were lacking within the system - consideration should be given to determine the extent of additional services required in these areas.

## **Smoking cessation programs**

There appears to be very limited smoking cessation programs (significantly less than in other jurisdictions), and GPs typically do not discuss smoking cessation with their patients. Aboriginal populations have the highest smoking rates, and there is a considerable lack of services and support for people from Culturally and Linguistically Diverse (CaLD) backgrounds in relation to smoking cessation.

## **Services in the home**

Examples include home ventilation, intravenous antibiotics and tracheotomy maintenance. These services are sometimes provided by Health Service Providers, and the availability of these services is variable based on geographical location. There are however relatively well-established home services for patients requiring domiciliary oxygen for advanced chronic respiratory conditions.

## **Specialists visiting rural areas**

There are very few specialists who visit rural areas, and there has been no overall needs-based assessment to determine where the demand for specialists is greatest.

## **Limited accessible information on respiratory conditions and community-based services**

Although there are a range of condition information and education services which are provided, a significant proportion of consumers, carers and clinicians consulted stated that they were unaware of the sources of information which are available to help them manage their condition.

Information which is available is often not user-friendly or is not tailored for people who struggle to read and/or access the internet. Information on co-morbidities and how to manage these is limited. There is also a lack of culturally appropriate materials to educate people and communities from Aboriginal and CaLD backgrounds.

There is also a significant lack of information in relation to community services which are available – for example, there is no service directory or other accessible source of information. HealthPathways provide some useful information, however feedback from consultees was that they are not frequently updated and are not consistently utilised by referrers.

Consumers, carers and clinicians consulted typically expressed a lack of knowledge of what community-based services are available, and/or a lack of clear understanding of how to access them. Service providers typically acknowledged that they lack the time and resources to effectively promote their services.

### **Lack of effective collaboration and integration of care**

There are some good examples of partnership working between organisations, but very limited collaborative service planning of community-based respiratory services, with the exception of some care collaboratives which have been established. There is a lack of a clear process to collaboratively design care models and commission services based on sufficient expertise and a robust understanding of priority needs, outcomes, and sustainability. This includes ensuring that an appropriately broad range of stakeholders are consulted, and their views accounted for.

There are significant challenges in the way that organisations communicate and collaborate during the patient pathway. For example, there is a lack of clear referral processes for community respiratory services, including a lack of clear criteria and understanding of the referral pathways. There is also an overall lack of integrated care coordination, communication and information for people transitioning between paediatric and adult services, and between acute and community care.

Consultees highlighted some opportunities for better communication and delivery of multi-disciplinary care through establishment of collaborative models such as community hubs.

In addition, there is a lack of an overall cross-organisational approach to manage lung health for Aboriginal people. Consultees stated that there is a need to work collaboratively to plan, develop and deliver culturally appropriate services, and to ensure staff have the right skills to engage with and treat Aboriginal people with respiratory conditions.

### **Areas of Focus**

The areas of focus that emerged from review of community based respiratory health services were split into two categories:

1. Service Development Areas – which relate to the priority service development gaps and proposed new and/or expanded services; and,
2. Identified Areas for Future Focus – which relate to other identified areas where further scoping must be undertaken to determine the work required to improve integrated care.

The needs within these two categories are outlined in further detail in the tables overleaf.

## Service Development Areas

Area of Focus	Theme addressed	Alignment to Sustainable Health Review
<p><b><i>Community-based physiotherapy and pulmonary rehabilitation services.</i></b></p> <ul style="list-style-type: none"> <li>Expand the number of community-based physiotherapy and pulmonary rehabilitation services provided in the community for children and adults</li> <li>Change the acceptance criteria for all community-based rehabilitation services to enable patients to be referred directly from a GP rather than having to be referred to a specialist first</li> </ul>	Access to key services	Recommendations 11a & 13
<p><b><i>Access to quality lung function testing in the community</i></b></p> <ul style="list-style-type: none"> <li>Improve the availability and quality of lung function tests being conducted in Western Australia</li> <li>Establish an ongoing quality control program for lung function testing</li> <li>Upskill clinicians to conduct lung function testing for a group of neighbouring GP clinics</li> </ul>	Access to key services	Recommendation 13
<p><b><i>Support for COPD diagnosis and management</i></b></p> <ul style="list-style-type: none"> <li>Enable community-based services to provide tailored support for people with COPD</li> </ul>	Access to key services	Recommendations 9, 11a & 13
<p><b><i>Support for people with mental health conditions related to respiratory health problems</i></b></p> <ul style="list-style-type: none"> <li>Improved community-based mental health services to support people with chronic conditions</li> <li>Increase clinician's awareness of available community-based mental health services and referral processes into these services</li> </ul>	Access to key services	Strategy 2

## Identified Areas for Future Focus

Area of Focus	Theme addressed	Alignment to Sustainable Health Review
<p><b><i>Improved patients, carers and clinicians' knowledge of respiratory conditions and services</i></b></p> <ul style="list-style-type: none"> <li>• Improve the health literacy of people with respiratory conditions and their carers / families through the use of education programs</li> <li>• Establish a service directory of all community-based respiratory services</li> <li>• Investigate and develop the role of pharmacists in the management of respiratory conditions</li> </ul>	Information on respiratory conditions and services	Recommendation 1
<p><b><i>Improved integrated care between primary care, secondary/tertiary care and community-based services</i></b></p> <ul style="list-style-type: none"> <li>• Establish a clear approach for collaborative service planning</li> <li>• Develop clear referral and patient transition processes that are user friendly and that provide accurate information</li> </ul>	Effective collaboration and integration of care	Recommendations 4, 10, 13 & 16
<p><b><i>Availability of and access to smoking cessation programs</i></b></p> <ul style="list-style-type: none"> <li>• Review of community-based smoking cessation programs in Western Australia</li> <li>• Increase GP awareness of existing community-based smoking cessation programs, and promote the importance of referring people to these programs</li> <li>• Following the detailed review and awareness raising, consideration should be given as to whether additional community-based smoking cessation programs need to be implemented</li> </ul>	Access to key services	Recommendation 1
<p><b><i>Access to comprehensive primary care to support lung health for Aboriginal people</i></b></p> <ul style="list-style-type: none"> <li>• Collaborative approach to reducing the prevalence of respiratory conditions and the burden of disease in Aboriginal populations</li> </ul>	Effective collaboration and integration of care	Recommendations 3, 25 & 26

Area of Focus	Theme addressed	Alignment to Sustainable Health Review
<ul style="list-style-type: none"> <li>• Work with Aboriginal training institutions to increase the capability and capacity of the Aboriginal healthcare workforce</li> </ul>		
<p><b><i>Exploring the development of community hubs where specialists and community providers can collaborate to offer a range of services to enable patient-centered care</i></b></p> <ul style="list-style-type: none"> <li>• Determine stakeholder appetite for community hubs</li> <li>• Develop preliminary outline design(s) for community hubs (subject to appetite)</li> <li>• Undertake feasibility assessment</li> </ul>	Effective collaboration and integration of care	Recommendations 10, 11a & 13

## Next Steps

Based on the findings of the review of community based respiratory health services in Western Australia outlined in this document, it is recommended that future procurement of community-based services is built on a specific set of outcomes for individuals with respiratory disease to ensure improvements in health and wellbeing are achieved.

The Respiratory Health Network of the Health Networks Unit of the Clinical Excellence Division will advise Purchasing and Contracting Unit of the Purchasing and System Performance Division of the outcomes of the review and collaborative work will be undertaken to ensure that future services procured will align with the service development areas.

The Respiratory Health Network will continue to work with its partners to further explore and scope the identified areas for future focus to ensure the most appropriate services are provided to people with respiratory conditions in the community.

## Appendix 1 Summary of Literature Review

### Respiratory Conditions

Condition	Prevalence / Health Needs	Service Needs
<b>Asthma</b>	<ul style="list-style-type: none"> <li>• Approximately 10% of people in WA have Asthma</li> <li>• Higher incidence in females living in outer regional areas</li> <li>• Higher incidence in lower socioeconomic areas</li> <li>• Higher prevalence in Indigenous populations (twice as high compared to non-Indigenous populations - observed across all age groups but more evident amongst older Indigenous adults), particularly in non-remote areas</li> </ul>	<ul style="list-style-type: none"> <li>• Use of preventer medication is one of the most effective strategies, however, it is often underused due to out of pocket costs</li> <li>• An increase in the number of diagnostic tests is required to ensure the right preventer medication is prescribed to patients, and better education is required to ensure patients use the proper inhaler technique</li> <li>• A significant proportion of asthmatic individuals (72%) do not have an Asthma Action Plan</li> <li>• There is a need for improved access to investigations such as spirometry for early and accurate diagnosis</li> <li>• There is also a need to improve the implementation of evidence based pulmonary rehabilitation, effective education and use of preventer therapist, and airway clearance &amp; exercise training</li> <li>• There is a need for ongoing and regular education for GPs, patients and carers to ensure better use of asthma medications</li> <li>• For CALD and Indigenous populations, self-management instructions and all written materials need to be clear and easy to read</li> <li>• Better collaboration and integration is required between tertiary and primary care service, in relation to management and referral of patients</li> <li>• For patients with severe asthma, a model of care that targets complex and varied needs is required</li> </ul>
<b>Bronchiectasis</b>	<ul style="list-style-type: none"> <li>• Age: majority of deaths up to age 49 are related to cystic fibrosis bronchiectasis. Over 55, more deaths are associated with COPD and pneumonia</li> <li>• Gender: hospitalisation rate for females is twice as high compared to males</li> <li>• Higher prevalence in lower socioeconomic areas</li> <li>• Higher prevalence in Indigenous populations (more common in rural / remote Aboriginal communities)</li> </ul>	<ul style="list-style-type: none"> <li>• The average length of stay in hospital where bronchiectasis is the primary diagnosis is twice as long as for all hospitalisations</li> <li>• There is significant under investigation and under treatment in Aboriginal communities</li> <li>• Treatment of bronchiectasis is ideally managed in the community with primary health care providers coordinating care - management may include short-term &amp; prophylactic antibiotics, physio, lifestyle modifications (i.e. increase physical activity, eliminate smoking), pneumococcal vaccinations or surgery.</li> <li>• Health practitioners should adhere to guidelines that advocate self-management practices for patients as advised in the Cochrane Review 2018</li> <li>• A multidisciplinary approach to chronic care with individualised case management is required for patients with moderate or severe bronchiectasis</li> <li>• There is a need for increased referral of patients to pulmonary rehabilitation, increased attention to airway clearance, increased collection of sputum and rationalisation of inhaled corticosteroid use</li> <li>• There is a lack of community-based services for patients with non-CF bronchiectasis</li> </ul>

Condition	Prevalence / Health Needs	Service Needs
<b>Chronic Obstructive Pulmonary Disease (COPD)</b>	<ul style="list-style-type: none"> <li>• Age: prevalence increases with age (mainly affecting those aged 45 &amp; older). Fourth most fatal burden for those aged 75 &amp; older in both sexes</li> <li>• Location: higher disease burden in very remote areas</li> <li>• Location: in metro area the greatest need for COPD was Balga-Mirrabooka (Stirling - SA2), which has a high proportion of CALD people (76.4% of population with a nationality other than Australian, and 42.9% born overseas)</li> <li>• Other hotspots in Clarkson, Bullsbrook, Midland-Guildford, Jane Brook, Armadale, Belmont-Victoria Park, Kwinana, Rockingham, Mandurah</li> <li>• Higher incidence in lower socioeconomic areas</li> <li>• Higher prevalence in Indigenous populations (3.4 times higher disease burden of all respiratory conditions)</li> <li>• Tobacco use contributes to 75% of COPD burden attributed to modifiable risk factors</li> </ul>	<ul style="list-style-type: none"> <li>• Majority of hospitalisations (72%) occur in country or regional areas. <ul style="list-style-type: none"> <li>◦ Hospitalisations in the Pilbara region are 5.2 times that of the state average</li> </ul> </li> <li>• There is a need for improved access to investigations such as spirometry for early and accurate diagnosis</li> <li>• There is a need for improved implementation of evidence based pulmonary rehabilitation, effective education and use of preventer therapist, and airway clearance &amp; exercise training</li> <li>• There is a need to provide culturally sensitive pulmonary rehabilitation training programs for health professionals working with Indigenous populations to improve access for patients in living in rural and remote areas</li> <li>• Educational activities to improve patient's health literacy is required to ensure comprehensive pulmonary rehabilitation, as they form the knowledge base for behaviour change, which leads to sustained positive outcomes for the patient</li> </ul>
<b>Respiratory Infection (refers to pneumonia, influenza &amp; common cold)</b>	<ul style="list-style-type: none"> <li>• Influenza causes 13,500 hospitalisations and more than 3,000 deaths per year in adults aged over 50</li> <li>• Indigenous Australians are at higher risk of pneumonia</li> <li>• Tobacco users are at higher risk of pneumonia</li> <li>• Patients with pre-existing medical conditions such as diabetes, cancer and other chronic conditions affecting the lungs, heart, kidney or liver are at higher risk of pneumonia</li> <li>• Unclear what long-term effects of COVID-19 will be - not yet anticipated that it will produce significant disease burden on the WA health system</li> </ul>	<ul style="list-style-type: none"> <li>• The average length of stay in hospital for people with pneumonia increases from 6 days for those under 65 and 13 days for those 65 &amp; older.</li> <li>• The annual flu vaccine is promoted as an important way to reduce flu infections</li> </ul>
<b>Interstitial Lung Disease</b>	<ul style="list-style-type: none"> <li>• Proportion of disease burden attributable to modifiable risk factors is 22%</li> <li>• Common comorbidities include gastro-oesophageal reflux disease, lung infections and pulmonary hypertension</li> <li>• Sleep-disordered breathing also contributes to pulmonary hypertension</li> </ul>	<ul style="list-style-type: none"> <li>• There is a lack of community-based services for patients with Interstitial Lung Disease</li> <li>• Recommendations for non-pharmacological management include: oxygen therapy, pulmonary rehabilitation and early palliative care support</li> </ul>

Condition	Prevalence / Health Needs	Service Needs
<b>Occupational Lung Disease</b>	<ul style="list-style-type: none"> <li>• No comprehensive population-based estimates of lung disease in Australia</li> <li>• Modifiable risk factors contribute to 100% of disease burden</li> <li>• Occupational exposure can account for 9% of the asthma burden</li> <li>• Gender: males are twice as likely to get the disease due to occupational preferences</li> </ul>	<ul style="list-style-type: none"> <li>• Requirement for ongoing monitoring and education in relation to: <ul style="list-style-type: none"> <li>○ The causes of Occupational Lung disease, such as exposures to hazardous materials, and</li> <li>○ Commission for Occupational Safety and Health and Worksafe WA guidelines</li> </ul> </li> </ul>
<b>Rare Lung Conditions</b>	<ul style="list-style-type: none"> <li>• Includes Cystic Fibrosis - one of the most common lethal genetic disease affecting Australians (1 in every 2,500 births produces a child that has Cystic Fibrosis in Australia)</li> <li>• Other examples include alpha-1 antitrypsin (AAT) deficiency and lymphangioleiomyomatosis (LAM)</li> <li>• Incidence of mental health issues for patients with Cystic Fibrosis are 2-3 times greater than the general population</li> </ul>	<ul style="list-style-type: none"> <li>• Hospitalisations for Cystic Fibrosis are common for up to three weeks at a time</li> <li>• Cystic Fibrosis patients require greater mental health support both at tertiary hospitals and in the community</li> <li>• There is a lack of home-based and local spirometry and treatment options available</li> <li>• There is a lack of mental health support services for people with respiratory conditions</li> </ul>
<b>Respiratory Lung Disease Overlap</b>	<ul style="list-style-type: none"> <li>• Patients with respiratory illness are often diagnosed with only one condition, however coexistence of multiple airway conditions associated with increased lung inflammation, worse lung function and higher mortality</li> <li>• Older patients more likely to be diagnosed with COPD without consideration of asthma</li> <li>• 30 - 60% of patients with severe COPD have concurrent bronchiectasis</li> <li>• 15-20% of patients with obstructive airway disease have been diagnosed with both asthma and COPD - also known as asthma-COPD overlap syndrome (ACOS)</li> </ul>	<ul style="list-style-type: none"> <li>• There is a need for symptom-based rather than disease-specific approach to management ("treatable traits approach"), particularly to enable precision medicine based on characteristics of disease presented, to optimise efficacy and minimise unnecessary side-effects</li> <li>• There is a need for services to understand comorbidities and treat patients holistically</li> </ul>

## Priority Populations

Priority Populations	Key Needs
Indigenous Populations	<ul style="list-style-type: none"> <li>• Health promotion programs are required to be tailored to Indigenous populations to ensure culturally safe programs</li> <li>• Provision of best practice care in remote Aboriginal health services is undermined by acute workloads, lack of health literacy, understaffing and high staff turnover</li> <li>• Lack of transport and accommodation in regional centres and major cities</li> <li>• Inequity in accessing culturally responsive services for Aboriginal populations with disabilities</li> </ul>
Culturally and Linguistically Diverse (CALD)	<ul style="list-style-type: none"> <li>• Key barriers to treating CALD patients include: language issues, accessibility and engagement of patients, poor health literacy, and cultural beliefs / issues</li> <li>• Significant factors as to why conditions such as asthma are not well controlled in these communities include: stigma, poor health literacy, non-adherence, expectations and coping styles</li> <li>• Health care costs and wait times are significant barriers in the CALD community</li> <li>• Requirement for cultural competence training for primary care physicians and pharmacists to provide cultural proficient care, and/or recruitment of health professionals from CALD communities or backgrounds</li> <li>• Requirement for education for CALD patients to enhance their health literacy, including literacy of health system navigation</li> <li>• Requirement to improve interpreting services, and improve health promotion and community services in general to increase cultural sensitivity</li> </ul>
People with Disability	<ul style="list-style-type: none"> <li>• Barriers to accessing community services include, mobility impairments, transport limitations, location (e.g. rural and remote communities) lack of specialist resources, cost, wait times, discrimination and lack of communication between health professionals</li> <li>• Cognitive impairment leads to increased levels of inhaler incompetence in COPD patients, lack of adherence to treatment and effective self-management, resulting in increased need for daily assistance</li> <li>• Requirement to improve the knowledge of health care workers, particularly nurses, caring for disabled people, especially those with intellectual disabilities</li> <li>• Requirement to support families in travel, responsive outreach programs and use of technology to improve service delivery and accessibility</li> </ul>
Older Populations	<ul style="list-style-type: none"> <li>• Aging related conditions affect Indigenous people at a younger age than non-Indigenous people</li> <li>• Require aged care services to take into account Indigenous population aged 50 and older, and 65 and older for non-Indigenous population</li> <li>• For population 65 and older, respiratory diseases were the third leading cause of disease burden for men, and fifth for women</li> <li>• Requirement to take into account a need for older populations that have a disability and require greater support</li> <li>• Requirement for good relationships between older individuals, their families and care providers to ensure autonomy in decision making (i.e. consumer-directed care - to provide greater choice and control of care services they receive, including development of a care plan)</li> </ul>

Priority Populations	Key Needs
Rural & Remote Populations	<ul style="list-style-type: none"> <li>• Poorer access to health services, high level of disease and lower life expectancies in rural and remote communities</li> <li>• Indigenous people are more affected as the proportion of this population increases with remoteness</li> <li>• Health inequities caused by challenges in accessing health care / specialists, social determinants (e.g. income, education and employment opportunities), higher rates of health risk behaviours (e.g. tobacco and alcohol use), and higher rates of occupational and physical risks (e.g. farming, mining and transport-related injuries)</li> <li>• Greater incidence of asthma, COPD and lung cancer in more remote areas</li> <li>• Barriers these populations face in accessing health services include: large geographical spread, long travel times, lack of transport options, limited social support and long wait times</li> <li>• Lack of use of support services by carers in regional areas due to inaccessibility, poor timing and lack of anonymity</li> <li>• Require use of information and communication technologies to save on travel time and expenditure for carers seeking support services</li> </ul>

## Appendix 2 Community Based Respiratory Service Mapping in Western Australia

The service mapping was undertaken as part of the consultation process and while every effort to collate a comprehensive map of services was undertaken, there may still be services that were not recorded in this mapping exercise.

Type of service	Locations / Organisations	Identified gaps
Pulmonary Rehabilitation	<ul style="list-style-type: none"> <li>WACHS provide a number of Cardiopulmonary rehabilitation services, particularly within the South West, Wheatbelt and Midwest.</li> <li>Bentley Health Service provides pulmonary rehabilitation for people with COPD, asthma, bronchiectasis, asbestosis, ILD and pulmonary fibrosis in a hospital setting.</li> <li>Rehabilitation in the Home (RITH) provides pulmonary rehabilitation for people with respiratory conditions in the Perth metropolitan region.</li> <li>Community Physiotherapy in the South, North and East Metropolitan Regions, which provide Phase 2 (initial program - attend twice weekly for 8 weeks) and Phase 3 (patients who require additional support - attend weekly for 10 weeks) pulmonary rehabilitation programs.</li> </ul>	<ul style="list-style-type: none"> <li>Lack of access to pulmonary rehabilitation in the home. For those that do exist, there is no clarity as to whether patients are actually completing their exercises.</li> <li>Stakeholder consultations suggested that there are very limited community-based services provided in south metro or further north (i.e. Joondalup).</li> <li>There is also a lack of community-based pulmonary rehabilitation services in rural / remote areas.</li> </ul>
Lung function tests	<ul style="list-style-type: none"> <li>Asthma WA provides a referral service to an external organisation for people with asthma and COPD to receive a lung function test. This is bulk billed and only provided in the Perth metropolitan area.</li> <li>Respiratory Testing Services offer comprehensive lung function testing in the Perth metro areas, as well as a large number of rural locations. The service can take place in a medical practice, hospital, an organisation's office, other health service provider offices (e.g. Black Swan or 360 health), and occasionally at a street doctor service.</li> <li>WACHS South West perform spirometry testing on the ward in Bunbury Hospital.</li> </ul>	<ul style="list-style-type: none"> <li>Lack of sufficient lung function testing being conducted by GPs.</li> <li>Whilst there are some community-based services that provide lung function testing, stakeholder consultations highlighted that there is an apparent lack of awareness amongst clinicians regarding these services.</li> </ul>
Education programs	<ul style="list-style-type: none"> <li>CFWA provides national and statewide education for schools / communities, teachers, all health professionals, regional nurses and physiotherapists. They also provide educational resources for parents, carers, people with CF and health professionals statewide.</li> <li>Asthma WA provides face to face education in the Perth metro area, and Telehealth education for asthma / COPD in rural / remote areas. Community workshops are also provided statewide to educate community organisations, workplaces and other services. Education provided is on inhaler technique, physiology of asthma / COPD, trigger management, respiratory first aid and action plans. Seminar presentations, community engagement / expos, Aboriginal education sessions, health professional upskilling, and teacher and student education in schools are also provided in the Perth metro area. Asthma</li> </ul>	<ul style="list-style-type: none"> <li>The service mapping highlighted that there are no specific education programs tailored for people with bronchiectasis.</li> <li>Significant gaps exist in relation to health literacy of Aboriginal people and those in rural / remote communities. This is also the case for those from lower socioeconomic areas and from CaLD backgrounds.</li> <li>Stakeholder consultations also highlighted that there is a lack of basic education coming from healthcare professionals (e.g. GPs, specialists and pharmacists) to people with respiratory conditions.</li> </ul>

Type of service	Locations / Organisations	Identified gaps
	<p>WA also provide the Asthma Kids Club service online statewide, which provides support and education activities for children and their parents.</p> <ul style="list-style-type: none"> <li>● Lung Foundation Australia provides consumer education webinars nationally for people with respiratory conditions and carers.</li> <li>● WAPHAs Chronic Respiratory Disease Telehealth service provide chronic respiratory disease education and clinical support via Telehealth for people living in regional WA with asthma and COPD. Similarly, their Chronic Disease Nurse and COPD Primary Acute Integration (Breathing Fresh Air into COPD) services provide support for people with COPD who are non-oxygen dependent and discharged from Joondalup Health Campus, as well as upskilling GPs to improve care and management of their people with COPD.</li> <li>● WACHS South West provide the Breathlessness Group service which educates people in the South West about lung conditions.</li> </ul>	
Training programs	<ul style="list-style-type: none"> <li>● CFWA provide competency-based spirometry training and a Regional Respiratory Training Program for nurses and physiotherapists statewide.</li> <li>● Asthma WA provide online sports coach training statewide for grass-roots coaches and people working in sport with children with asthma.</li> <li>● Australian Physiotherapy Association provide a professional development program that trains and upskills physiotherapists in optimal techniques for maintenance and management of respiratory health, particularly in individuals with muscle weakness and complex disability.</li> <li>● Lung Foundation Australia provide a number of evidence-based training programs for health professionals in a variety of modes, including online and face-to-face.</li> </ul>	<ul style="list-style-type: none"> <li>● Whilst some spirometry training does exist, this is predominantly targeted at healthcare professionals in regional areas. Other programs have to be specifically requested by healthcare professionals.</li> </ul>
Mental health services	<ul style="list-style-type: none"> <li>● CFWA provide parent, carer and sibling events (e.g. parent's retreat, sibling camp) statewide, and provide hospital visits and support for parents in the metro region. They also provide statewide community-based psychosocial support (e.g. counselling, general support, and coaching).</li> </ul>	<ul style="list-style-type: none"> <li>● There is a significant lack of community-based mental health services for people with respiratory conditions both in the metropolitan area, as well as in rural / remote areas.</li> </ul>
Support groups	<ul style="list-style-type: none"> <li>● CFWA provide parent, carer and peer support statewide through Facebook, webinars, resources, website, stories and short films.</li> <li>● Lung Foundation Australia provide the Affiliated Peer Support Groups (currently five in WA) for people in WA with general lung disease. They also provide Peer Connect for Pulmonary Fibrosis, a Telephone Support Group for Lung Cancer, and an information and support centre for all lung conditions nationally.</li> <li>● Silver Chain's COPD Community Support Program provides education and support for clients with COPD admitted to Joondalup Health Campus to improve</li> </ul>	<ul style="list-style-type: none"> <li>● Although some formal support groups do exist, consumer consultation sessions highlighted the apparent lack of awareness of these groups. This might mean more promotion is required to ensure people who require support are able to access it.</li> </ul>

Type of service	Locations / Organisations	Identified gaps
	<p>self management. Aim is to integrate patients post discharge care with primary health and community-based services, and provide GP education.</p> <ul style="list-style-type: none"> <li>● Rockingham Lung Support Group is a community-based support group in the South Metropolitan Region for people suffering from chronic lung conditions.</li> <li>● Consumer consultations highlighted that informal Facebook groups also exist.</li> </ul>	
In-home care	<ul style="list-style-type: none"> <li>● CFWA provide a number of home-based support services (e.g. airway clearance, exercise, respite, behaviour management, routines &amp; adherence, clearing, and general support) for people with CF in the metro area.</li> <li>● Silver Chain provide a respiratory care nursing service for people with respiratory conditions that require oxygen therapy. They have a networked team of nurses, physiotherapists, dieticians, social workers and respiratory physicians to help people manage their conditions.</li> <li>● Silver Chain also provide a Home Hospital service, which provides high-level acute care (e.g. IV antibiotics) in a patient's home or community clinic, rather than a hospital setting.</li> </ul>	<ul style="list-style-type: none"> <li>● Whilst the service mapping identified that some in-home care services do exist, consumer consultations highlighted some key accessibility issues for people who live beyond a certain region.</li> </ul>
Care coordination/ health navigator	<ul style="list-style-type: none"> <li>● Lung Foundation Australia provide a national Respiratory Care Nurse telephone service (three calls over four months) for people with COPD or bronchiectasis. The nurse provides guidance on all aspects of the condition and aims to connect people with information and support.</li> <li>● WAPHAs Integrated Chronic Disease Care service supports clients in remote areas with a care coordinator who links them to allied health services they need to better manage their condition. WAPHAs Integrated Team Care service provides support to Aboriginal people who have existing chronic condition/s and require additional support. WAPHAs Respiratory Care Coordination service provides support and information in the home for people with advanced respiratory disease who require domiciliary oxygen, in the North and South Metropolitan regions.</li> <li>● WACHS, WAPHA and Silver Chain are part of a collaborative chronic conditions group, which is working to provide a Chronic Conditions Care Coordination service throughout all regions in WA to assist with navigation and self-management education.</li> <li>● Silver Chain provide a Health Navigator service, which is a free phone service designed to help people with chronic conditions, including chronic lung conditions, such as COPD to get their health back on track. It is available to people who live in the Wheatbelt, Great Southern or South West, as well as those living with one or more chronic conditions.</li> </ul>	<ul style="list-style-type: none"> <li>● Lung Foundation Australia's service is only provided for people with COPD or bronchiectasis, and not other lung conditions.</li> <li>● WACHS care coordination services are not well advertised.</li> <li>● The Health Navigator service does not reach those in rural / remote communities in WA. It is currently only in the South West, Great Southern, Wheatbelt and Perth metropolitan regions.</li> </ul>

Type of service	Locations / Organisations	Identified gaps
Smoking cessation programs	<ul style="list-style-type: none"> <li>WACHS provide a Quit Smoking Program for current smokers intending to quit in the next three months. It provides an assessment, education and counselling. The locations highlighted through the service mapping included the Wheatbelt and Carnarvon in the Midwest.</li> </ul>	<ul style="list-style-type: none"> <li>The service mapping and stakeholder consultations suggested that only WACHS provide smoking cessation programs.</li> <li>Further investigation highlighted that whilst numerous promotional campaigns and educational programs exist, there are very few comprehensive smoking-cessation programs.</li> </ul>
Respiratory outreach	<ul style="list-style-type: none"> <li>Respiratory Consultant provides comprehensive respiratory assessment and management closer to home. Particularly in the Great Southern and Wheatbelt for consultations, and almost the entire state for lung function testing.</li> <li>PCH provide some regional specialist respiratory outreach to the Kimberley region.</li> </ul>	<ul style="list-style-type: none"> <li>There are very few respiratory outreach services for rural / remote areas, apart from those living in the Great Southern and Wheatbelt regions.</li> </ul>
Domiciliary oxygen	<ul style="list-style-type: none"> <li>Silver Chain provide community-based management and support from a team of nurses and social workers for people prescribed domiciliary oxygen and living in their own home within the Perth metro region.</li> <li>WACHS South West provide a domiciliary oxygen clinic in Bunbury Hospital that covers the South West, as part of their Chronic Conditions Care Coordination Service. It is provided for any conditions meeting state guidelines to require oxygen.</li> </ul>	<ul style="list-style-type: none"> <li>Oxygen prescription comes from specialists, so communication to link in all health professionals in patients care is required.</li> <li></li> </ul>
Palliative care	<ul style="list-style-type: none"> <li>Great Southern Palliative Care has an integrated palliative care service that supports people in their own homes, residential aged care facilities, the inpatient setting and hospice.</li> <li>Silver Chain provide specialist palliative care and in-home hospice care services across the Perth metro area for people with life-limiting illnesses / conditions. However, access to hospice service remains limited due to resource constraints.</li> </ul>	<ul style="list-style-type: none"> <li>The review of literature and stakeholder consultations highlighted issues regarding lack of access, and timely referral and engagement with palliative services or advanced care planning.</li> </ul>
Sleep services	<ul style="list-style-type: none"> <li>GenesisCare Sleep and Respiratory is a statewide private service that aims to help with ongoing management of chronic respiratory conditions (e.g. COPD, asthma, ILD, pneumonia and bronchiectasis).</li> </ul>	<ul style="list-style-type: none"> <li>There is an overall lack of community-based sleep services, in particular, ones that bulk bill. Currently, the majority of sleep services are provided in a tertiary setting and have long wait times.</li> <li>Stakeholder consultations also highlighted that there are considerable costs for people to access the required machines.</li> </ul>
Discharge planning	<ul style="list-style-type: none"> <li>Silver Chain provide a Hospital Discharge Support service, which uses the allied health team to assess a patient in their home and design a short-term program around their goals.</li> </ul>	<ul style="list-style-type: none"> <li>There is a lack of community-based services to support discharge planning. Very few have any form of</li> </ul>

Type of service	Locations / Organisations	Identified gaps
		collaboration with hospitals to support the patient following discharge from hospital.
Equipment provision	<ul style="list-style-type: none"> <li>CFWA provide statewide equipment to people with CF in the form of nebulisers, trampolines, and exercise equipment.</li> </ul>	<ul style="list-style-type: none"> <li>Other than that provided by CFWA for people with cystic fibrosis, there is an overall lack of services that provide any form of equipment for people with respiratory conditions.</li> </ul>
Emergency relief	<ul style="list-style-type: none"> <li>CFWA provide statewide relief in the form of food, clothing, referrals to Foodbank, and financial subsidies for people with CF or carers / parents of someone with CF.</li> </ul>	<ul style="list-style-type: none"> <li>Other than that provided by CFWA for people with cystic fibrosis, there is an overall lack of services that provide emergency relief for people with respiratory conditions.</li> </ul>

## Appendix 3 Stakeholders Consulted

Name	Role	Organisation
Li Ping Chung	Clinical Lead, WA Respiratory Health Network; and Respiratory Consultant	Department of Health; Fiona Stanley Hospital; Silver Chain
Gendy King	Manager, Strategic Policy	Aboriginal Health Policy Directorate, Public and Aboriginal Health Division, DoH
Jeanie Leong	Head of Department	Royal Perth Hospital
Mike Musk	Head of Department	Fiona Stanley Hospital
Fraser Brims	Head of Department	Sir Charles' Gairdner Hospital
Andrew Wilson	Head of Department	Perth Children's Hospital
Justin Waring	RPH Clinician, Director of Anita Clayton Centre, Bronchiectasis expert	Royal Perth Hospital
Grant Waterer	RPH Clinician, Service Director RPH, Bronchiectasis expert	Royal Perth Hospital
Annie O'Donnell	Paediatrician PCH, Director Sleep Services PCH, private physician	Perth Children's Hospital & Private Physician
Pamela Laird	Senior Respiratory Physiotherapist	Perth Children's Hospital
Vivienne Travlos	Lecturer Paediatric Physiotherapy; Physiotherapist	University of Notre Dame; Child and Adolescent Health Service
John McLachlan	FSH clinician, Clinical Lead Pulmonary Physiology & Sleep Medicine	South Metropolitan Health Service; Fiona Stanley Hospital
Sharon Lagan	A/Chief Respiratory Scientist, and Lead for Spirometry working group.	Royal Perth Hospital
John Blakey	SCGH Clinician, Curtin Academic for Research	Sir Charles' Gairdner Hospital / Curtin Research
Vin Cavalheri	Allied Health Research Director	South Metropolitan Health Service; Curtin University
Jenny Howson	General Manager Health Services	Asthma WA
Donna Rendell	CEO	Asthma WA
Nigel Barker	CEO	Cystic Fibrosis WA

<b>Name</b>	<b>Role</b>	<b>Organisation</b>
Dan Norgard	General Manager	Silver Chain
Mark Brooke	CEO	Lung Foundation
Marianne Wood	Public Health Medical Officer	Aboriginal Health Council of Western Australia
Tony Fotios	Metro Operations Manager	WA Primary Health Alliance
Kate Cross	Country Operations Manager - South	WA Primary Health Alliance
Sue Lee	Regional Manager	WA Primary Health Alliance
Clare Mullen	Engagement Manager	Health Consumers Council (organised consumer consultation session)
Terina Grace	CEO	Black Swan
Dorika Nhongo	Chronic Disease, Mental Health & Aged Care Manager	360 Health
Siobhain Mulrennan	Cystic Fibrosis Physician & EAG Member	Sir Charles' Gairdner Hospital & Executive Advisory Group Member
Tina Tuira-Waldon	Carer Representative	Executive Advisory Group Member
Robert Blakeman	Carer Representative	Carers WA; Executive Advisory Group Member
Charlotte Steed	Chronic Conditions Care Coordinator	WA Country Health Service; Executive Advisory Group Member
Renate Jolly	Clinical Nurse Consultant Respiratory	Royal Perth Hospital; Executive Advisory Group Member
Su Lyn Leong	Respiratory Consultant	Rockingham General Hospital; Executive Advisory Group Member
Gemma Johnston	GP Registrar	Kimberley Aboriginal Medical Service; Executive Advisory Group Member
Kristy Tilden	Clinical Nurse Consultant Manager	Silver Chain; Executive Advisory Group Member
Corey Lei	GP Clinical Editor	WA Country Health Service; Executive Advisory Group Member
Kate Hawkings	Chronic Conditions Coordinator and Acting Telehealth Manager	WA Country Health Service
Nicole Jeffree	Senior Project Officer	WA Country Health Service
Leesa Thomas	General Manager	Rural Health West
Caitlin Bradley	Manager of Outreach and Regional Services	Rural Health West

<b>Name</b>	<b>Role</b>	<b>Organisation</b>
Kendra Mutch	Senior Project Officer - Chronic Conditions	WA Country Health Service
John Fitzgerald	Chronic Disease Coordinator / Senior Project Officer - Chronic Conditions	WA Country Health Service Midwest / WA Country Health Service
Carolyn Adams	Senior Physiotherapist	Community Physiotherapy services
Kylie Hill	Associate Professor	School of Physiotherapy & Exercise Science, Curtin University
Peta Winship	Physiotherapist	Belmont City Physiotherapy
Bryn Moulds	Physiotherapist	Geraldton
Nola Cecins	Physiotherapist	Sir Charles Gairdner Hospital
Shaun Guy	Physiotherapist	Collie
Anita Dinsdale	Physiotherapist	CPS
Holly Landers	Physiotherapy Manager	Joondalup Health Campus
Carol Watson	Physiotherapist	Royal Perth Hospital
Julie Depiazzi	Senior Respiratory Physiotherapist	In relation to cystic fibrosis
Irene Dolan	General Practitioner	Ellen Health
Kyria Laird	GP Clinical Editor	Health Pathways, WA Primary Health Alliance
Linda Kohler	GP Clinical Editor	Health Pathways, WA Primary Health Alliance
Agnieszka Etubus	GP Clinical Editor	Health Pathways, WA Primary Health Alliance
Danni Rebbettes	GP Clinical Editor	Health Pathways, WA Primary Health Alliance
Richa Tayal	GP Clinical Editor	Health Pathways, WA Primary Health Alliance
Andre Schultz	Paediatric Physician; and Director of Cystic Fibrosis	Perth Children's Hospital
Consumer and Carer Representative	Group of consumers n=8	Health Consumers' Council
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