Stocktake of Australian activities  
in lung disease

## A stocktake of activities that are occurring in Australia in the area of lung diseases, to inform the development of the National Strategic Action Plan for Lung Conditions

## August 2018

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Executive summary

This document, together with the accompanying spreadsheet, provides a comprehensive account of current Australian activities in the area of lung diseases. The lung diseases encompassed in this stocktake include Asthma, COPD, Bronchiectasis, Interstitial lung disease, Pulmonary Fibrosis, Cystic Fibrosis, Lung cancer, Occupational Lung disease, Obstructive Sleep Apnoea, Tuberculosis.

The present report provides a brief summary of the identified activities, collated under the five broad priority areas outlined in the Draft Framework for the National Strategic Action Plan for Lung Health: (1) preventing lung conditions; (2) Increasing awareness and reducing stigma; (3) Empowering people to take an active role in their health; (4) Promoting equitable access to evidence-based care; and (5) Addressing the knowledge gaps.

To accompany this report, an Excel spreadsheet has also been provided, which includes:

* Further details of all the activities collected via an electronic survey of stakeholders (e.g. brief descriptions of the nature of the activity, the funding body and location)
* A list of additional activities identified through active searching
* A list of research projects currently being undertaken in Australia in the area of lung diseases.

Overall, the stocktake identified many and varied activities occurring in Australia in the area of lung conditions at the national, state/territory and local level. They include awareness campaigns, prevention programs, research, education courses for patients and health professionals, support groups, information centres, screening centres, specialist services, clinics (including outreach clinics), registries and many more. Some activities, such as multidisciplinary clinics for specific lung diseases or conditions, occur in multiple locations within individual health systems. These vary in terms of staffing, reach and services provided.

In terms of coverage of the priority areas listed in the Draft Framework, we found many activities that were focussed on areas such as patient support, reducing smoking rates, and the provision of pulmonary rehabilitation. On the other hand, we could only map a few activities in the area of reducing stigma and discrimination.

This stocktake identified numerous clinical guidelines and standards relevant to lung disease, that are available to health care professionals and patients. However, these were collated from multiple different sources, and there was no single site from which one could identify the most recent, widely recommended or best-referenced guidelines within each lung disease. This gap could potentially be addressed by establishing a ‘one-stop shop’ approach to guidelines for lung disease to assist health care practitioners and patients. For example a web-page that hyperlinked to the most appropriate guidelines and that was regularly updated would be a very useful resource. This would also help to identify which Australian guidelines are lacking or are overdue for update.

In the same way, the process of undertaking this stocktake has highlighted that policy-makers, researchers, clinicians and the general public could all benefit from the availability of central repositories which would provide up-to-date links and/or lists of:

- Standards of care for all lung conditions  
- Clinical trials currently underway for all lung conditions  
- Research projects in the field of lung conditions.

These could facilitate easy access to the latest information in the lung diseases space, the exchanging of ideas, the identification of any gaps in research as well as aiding in the standardisation of clinical resources for health care.

There are a number of research collaborative organisations and structures working in the field of lung disease. Lung disease appears to be well represented amongst NHMRC Centres of Research Excellence. Nationally, there are 7 *Advanced Health Research and Translation Centres* and an additional two *Centres for Innovation in Regional Health*. All of these entities are well placed to develop research capacity and promote research collaboration in lung disease. The two AHRTC’s in Sydney each have themes addressing lung disease. For example, working with just these two Sydney entities to implement a National Strategy in Lung Disease would provide cover of most Sydney Local Health Districts, Medical Research Institutes and Universities.

The 31 Primary Health Networks (PHNs) provide coverage of all of Australia. These are encouraged undertake local needs analyses and have the capacity to carry this out. Linking in with the PHNs presents an additional opportunity to understand local needs in lung disease. When the National Strategy has been implemented the PHNs will provide a useful channel for communicating with local primary health care services around Australia.

This report, while not exhaustive due to the short time frame and resource constraints, provides a comprehensive snapshot of activities and services relating to asthma, COPD, bronchiectasis, interstitial lung disease, pulmonary fibrosis, cystic fibrosis, lung cancer, occupational lung disease, obstructive sleep apnoea, and tuberculosis in Australia at the present time. Over 200 activities and services were identified at the national, state/territory and local level, providing examples of opportunities to build on existing models, and demonstrating areas in which further resources and services are needed in order to improve lung health in Australia.

Methods of data collection

To identify suitable activities for inclusion in the stocktake, two main methods were used – (1) an electronic survey of stakeholders, which was sent out to various recipients involved in numerous aspects of lung disease health and (2) active web-searching by ACAM staff.

ELECTRONIC SURVEY OF STAKEHOLDERS

A simple electronic survey for the collection of stocktake data was developed using SurveyMonkey. Feedback was received from LFA and colleagues and this was incorporated in the final Survey tool.

The SurveyMonkey tool allowed the input of up to 3 activities in the stocktake at a time. If a respondent had more than 3 activities to include, they could access the survey again to include the additional activities. For each activity entered in the stocktake via SurveyMonkey, information was collected about:

* The name of the activity
* The target audience
* The aim of the activity
* A brief description of the activity
* Who was/is running the activity
* The funding body
* The locality of the activity (national/state or territory/local or regional/other)
* The year the activity started
* The duration of funding
* The approximate number of people who had accessed the activity in the last year.

Suitable recipients were identified from web searches, colleagues as well as personal networks. The recipient list included peak bodies (e.g. Lung Foundation Australia, National Asthma Council Australia, Asthma Australia, Australian Respiratory Council, Cystic Fibrosis Australia), professional societies (e.g. ANZSRS, TSANZ, ASCIA, Royal Australian College of General Practitioners, Royal Australian College of Physicians, Australian Physiotherapy Association, Australian Nursing and Midwifery Association, Australian Primary Health Care Nursing Association, Allied Health Professions Australia, Pharmaceutical Society of Australia, The Pharmacy Guild of Australia, Mental Health Professionals Network), NPS MedicineWise, health organisations and services (e.g. National Aboriginal Community Controlled Health Organisations, Primary Health Networks, Aboriginal Community Controlled Health Services, State and Territory Health Departments, Local Health Districts and disease-focussed clinics in public hospitals), researchers, research and translational organisations (e.g. NHMRC Centres of Research Excellence and Advanced Health Research and Translational Centres), clinicians, pharmaceutical companies with respiratory products, personal contacts.

Initiatives, activities, programs and services currently occurring in Australia in the area of acute and chronic lung diseases will be identified by a range of methods including contacting national/state/territory health departments, advocacy groups including Lung Foundation Australia, professional bodies (e.g. TSANZ), personal contacts/networks, and authors of published local studies by phone and/or email.

An initial email, which included a link to provide input to the stocktake via SurveyMonkey, was sent between 27 July and 2 August 2018. A reminder was sent on 8 August 2018 and this reminder email included some specific examples of activities that would be appropriate to include. This reminder was sent to 392 recipients. A ‘last chance’ email reminder was sent on 17 August 2018 to 479 recipients. This email extended the initial deadline by a few days, included extra examples of activities and included a list of diseases that we were interested in collecting information about.

By Thursday 23 August, we had received 121 SurveyMonkey entries, with details of 201 activities entered.

ACTIVE SEARCHING METHODS

We also actively searched for activities that were suitable to include in the stocktake via general web searches (Google).

COLLATING THE DATA

The data received from the two methods described above was collated using the National Strategic Action Plan for Lung Health Draft Framework (see next page) to guide placement of the activities. The activities were collated according to the priority area, and then, further, by the relevant objective under that priority area (see Draft Framework).

NATIONAL STRATEGIC ACTION PLAN FOR LUNG CONDITIONS: DRAFT FRAMEWORK

**GOAL** *To improve the lives of all Australians through effective prevention and equitable access to management of lung conditions.*

| **Priority Area 1**  Health promotion and preventing lung conditions | **Priority Area 2**  Increasing awareness and reducing stigma | **Priority Area 3**  Empowering people to take active role in their health | **Priority Area 4**  Promoting equitable access to evidence-based care | **Priority Area 5**  Addressing the knowledge gaps |
| --- | --- | --- | --- | --- |

**OBJECTIVES**

| Promote good lung development | Raise awareness about lung diseases | Increase awareness of symptoms of lung disease to prompt timely action | Facilitate evidence-based diagnostic testing and use of appropriate referral pathways | Increase capacity of lung researchers |
| --- | --- | --- | --- | --- |
| Promote physical activity and healthy diet | Reduce stigma/discrimination | Promote shared decision making | Ensure equitable access to specialised care, where needed | Mine existing data and improve data linkages |
| Reduce Occupational Lung Disease |  | Support development and implementation of decision support tools and use of technology | Reduce variation in care by promoting adherence to evidence based care (includes clinical guidelines) | Promote systems that provide feedback on practice for improvement. |
| Increase immunisation rates |  | Provide information about triggers | Facilitate workforce Development | Facilitate research collaboratives. |
| Reduce Smoking rates |  | Facilitate social connectedness of those with lung conditions | Widen access to other services, including pulmonary rehabilitation | Ensure patient access to clinical trials |
| Improve air quality |  |  | Facilitate affordable access and timely access to proven medications | Increase the investment in lung health research |
|  |  |  | Adopt a national approach to domiciliary oxygen |  |
|  |  |  | Facilitate equitable access to supportive and palliative care |  |

Priority Area 1 – Health promotion and preventing lung conditions

1.1 PROMOTE GOOD LUNG DEVELOPMENT

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Indigenous Counselling and Nicotine (ICAN) QUIT in Pregnancy | Expectant mothers of Indigenous babies.  A step-wedge randomised trial in 6 services, provided with culturally-competent educational resources package, and webinar training for health providers in smoking cessation care. | University of Newcastle (A/Prof G Gould) |
| Investing in the Early Years – A National Early Childhood Development Strategy 2009 | A collaborative effort between the Commonwealth and the state and territory governments to ensure that by 2020 all children have the best start in life to create a better future for themselves and for the nation.  (Programs: New Directions, Mothers and Babies Services, Australian Nurse Family Partnership, Strong Fathers Strong Families and Healthy for Life). | An initiative of the Council of Australian Governments |
| Long term lung health for survivors of pre-term birth | To understand the long term impact of very preterm birth on lung health (longitudinally). Longitudinal lung function, imaging and biomarkers from 200 preterm (<32 w gestation) and 67 term controls | Telethon Kids Institute |
| The National Aboriginal and Torres Strait Islander Health Plan 2013-2023 | An evidence-based policy framework designed to guide policies and programmes to improve Aboriginal and Torres Strait Islander health over the next decade until 2023. | Australian Government Department of Health |
| National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes (2009-2013) | This agreement sets out specific action to be taken by the Australian Government and complementary action by State/Territory governments to address the gap in health outcomes experienced by Aboriginal and Torres Strait Islander people.  To address these issues, this Agreement is centred on five priority areas: tackling smoking, providing a healthy transition to adulthood, making Indigenous health everyone’s business, delivering effective primary health care services and better coordinating the patient journey through the health system. | Council of Australian Governments (COAG) |
| PIFCO (Preterm Infant Functional and Clinical Outcomes) | Investigating early life contributors to poor respiratory health after very preterm birth.  The main goal of the study is to learn more about how the heart, lung and breathing muscles contribute to breathing problems in babies born at less than 32 weeks gestational age. We also want to understand how other issues that arise during pregnancy and after birth contribute to development of lung disease in infants. Infants are being prospectively followed over the first year of life. | King Edward Memorial Hospital / UWA/ Telethon Kids Institute / Perth Children's Hospital |
| Quit for you - Quit for Two | A Quit smoking app for mums-to-be.  The app targets pregnant women, those planning to have children, and their partners, to help them give up smoking and give their children a healthy start in life. The campaign was developed by the Department of Health and Ageing and provides information about the health harms associated with smoking during pregnancy, and the support available to women on their journey to quit smoking. | Australian Government |
| SISTAQUIT (Supporting Indigenous Smokers To Assist Quitting) | An RCT aimed at expectant mothers of Indigenous babies, and Indigenous babies to support smoking cessation in pregnant mothers. Participating medical services are randomised to receive the intervention services (free webinar training for all GPs, Nurses/Midwives and Health Professionals, a free pack of resources for facilitating smoking cessation support to pregnant Aboriginal and Torres Strait Islander women) either at start of study or end of study. Mothers are followed up for smoking cessation outcomes. Babies are followed up to 6 months for respiratory symptoms. | University of Newcastle (A/Prof G Gould) |

1.2 PROMOTE PHYSICAL ACTIVITY AND HEALTHY DIET

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| ActionPACT: trial of physical activity promotion in people with cystic fibrosis | People with cystic fibrosis who have recently had a hospital admission. Randomised controlled trial comparing physical activity promotion with a web-based platform to usual care in adolescents and young adults with CF who have recently had a hospital admission. | Anne Holland CI with a team from La Trobe University |
| Active living fitness program | Older people with COPD and CCF are provided with free access to a community based fitness program (‘Lungs in Action’ program) developed for people with stable chronic lung conditions who have completed rehabilitation to keep them well, socially connected and out of hospital. | Central and Eastern Sydney PHN |
| Exercise as a therapeutic tool in the management of mesothelioma | Clinicians at the Institute for Respiratory Health are investigating the development of an intervention designed to counteract the aetiology of poor outcomes, enhance quality of life, and improve daily functioning in patients with mesothelioma. This could prove to have a highly significant impact on clinical care.  Exercise has the unique potential as an intervention to reduce functional decline and provide a non-invasive supportive intervention for those with malignant pleural disease. | Institute for Respiratory Health, WA |
| Lungs in Action Exercise Group | A safe exercise class suitable for people using supplemental oxygen and / or walking frames. There are seated options for every exercise. Patients can find their nearest Lungs in Action Exercise Group by referring to the Lungs in Action Map:  https://www.google.com/maps/d/viewer?mid=1knWFOcM17tOSN36nvmn2C4q1QML3ke8R&ll=-25.330223890067305%2C127.98736549999998&z=4 | Developed by Lung Foundation Australia and commissioned by NBMPHN. |

1.3 REDUCE OCCUPATIONAL DISEASE (SAFE WORKPLACES)

Several activities directed at reducing occupational disease were identified. The table below does not include activities by Unions or advocacy by LFA/TSANZ etc.

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| ADRI Biobank | The ADRI Biobank is the biorepository of the Asbestos Diseases Research Institute, a not-for-profit organisation with the mission to investigate the epidemiology of asbestos related lung diseases and to improve the diagnostic and preventative measure in these diseases. The overall aim of the ADRI Biobank is to provide approved investigators and collaborators with high quality biospecimens and data in order to improve the diagnosis and treatment of asbestos-related diseases and to contribute to effective preventive measures. | Asbestos Diseases Research Institute (ADRI) |
| Asbestos Review Program | The Asbestos Review Program (ARP) is a dedicated clinic to follow up people who have worked with, or who have had significant exposure to, asbestos.  The clinic has been running since 1990 and specialises in dealing with asbestos-related lung diseases. At the ARP arrangements are made for an annual health check-up using specialist breathing tests, blood tests and, the latest CT scan technology. The careful use of a low-dose CT scans of the chest can identify lung cancer at an early stage when it is potentially curable and the ARP offers this test. The clinic also has extensive experience in dealing with other lung diseases that asbestos exposure can cause. | Institute for Respiratory Health, WA |
| Australian IPF Registry | Collection on a national level of patients with an IPF diagnosis in order to establish a comprehensive data pool to use for research into the disease. This includes, genomics, biomarker, QOL and treatment research projects. The main premise is to understand more about the disease, causes and management. Aimed at patients and clinicians. | LFA |
| Australian Mesothelioma Register (AMR) | The AMR is a stand-alone database that contains information about people with mesothelioma. All new cases of mesothelioma diagnosed from 1st July 2010 in Australia are monitored. In addition, information about asbestos exposure is collected from people with mesothelioma through the Postal Questionnaire and telephone interview. | AIHW, funded by Australian Government agency Safe Work Australia |
| Department of Natural Resources, Mines and Energy (DNMRE) | The Department of Natural Resources, Mines and Energy (DNRME) has been working closely with the Queensland Office of Industrial Relations to capture workers' compensation data to accurately understand the prevalence of the disease across the coal, minerals and quarrying industries.  In order to have a complete picture of occupational lung disease in the mining industry, DNRME reports on all confirmed cases of mine dust lung diseases (including coal workers’ pneumoconiosis, COPD, silicosis and asbestosis). | DNMRE and Queensland office of Industrial Relations |
| GUARD (Genetic Understanding of Asbestos-Related Disorders) | GUARD will create a large scale DNA bank for mesothelioma and other asbestos-related diseases, linking WA cohorts with others from around Australia. | National Centre for Asbestos-Related Disease |
| Guideline for management of respirable crystalline silica in Queensland mineral mines and quarries (May 2018, Version 2.0) | Provides guidance on how to manage the monitoring of workers’ exposure to respirable crystalline silica (RCS) and to manage their health surveillance to achieve an acceptable level of risk from the hazard of exposure to RCS associated with mining silica bearing minerals and rock.  https://www.dnrm.qld.gov.au/\_\_data/assets/pdf\_file/0006/1263669/qgl02-guideline-mines-quarries.pdf | Queensland Government |
| Medical Screening Service | To provide respiratory health monitoring for Dust Diseases Care clients and current workers | icare NSW Dust Diseases Care |
| National Strategic Plan for Asbestos Management and Awareness (2015) | The Asbestos Safety and Eradication Agency has worked with state and territory governments to revise this National Strategic Plan for Asbestos Management and Awareness to ensure that right around Australia, we are working together to reduce the risks posed by asbestos and deliver a plan that represents the expertise and experience of government, industry and the community. | Asbestos Safety and Eradication Agency |
| The NSW State-wide Asbestos Plan: A plan to secure the safe management of asbestos in NSW (2013) | The NSW State-wide Asbestos Plan is a government initiative aimed at securing the safe management of asbestos to reduce the incidence of asbestos-related diseases in NSW.  The State-wide Asbestos Plan is a call to action to all those in government, industry and the community to responsibly manage asbestos throughout its lifecycle, and through research to endeavour to find better mitigation and management controls and effective treatment of asbestos-related diseases.  The State-wide Asbestos Plan has been coordinated by the Heads of Asbestos Coordination Authorities and developed in consultation with key government agencies, local council authorities, industry representatives, employee representatives, researchers and asbestos diseases groups. | WorkCover NSW |
| Occupational monitoring |  | Department of the Environment and Energy |
| Prevention of lung disease in coal mine workers | Queensland coal mine workers. Monash University conducted a review of the Respiratory Health Surveillance program for Qld coal miners and made several recommendations to improve the program and better detect such lung conditions at an earlier stage. This has included development of clinical guidelines to follow up respiratory abnormalities, which are being written by a collaborative group of TSANZ, AFOEM and RANZCR. | Monash, TSANZ, AFOEM, RANZCR |

1.4 INCREASE IMMUNISATION RATES

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Aboriginal and Torres Strait Islander specific immunisation programs | Aboriginal and Torres Strait Islander people are able to get extra immunisations for free through the National Immunisation Program (NIP) to protect against serious diseases. These extra immunisations are in addition to all the other routine vaccinations offered throughout life (children, adults, seniors, pregnancy).   * Pneumococcal disease (additional booster in children aged 12-18 months in Qld, NT, WA and SA) * Influenza (free for all Aboriginal and Torres Strait Islander children aged 6 months to 5 years through the NIP, free for those aged 15+ years). Flu vaccinations are also free for pregnant women. * Free catch-up vaccines for any missed routine childhood vaccinations   (see also the entry on the *National Immunisation Program* below) | Australian Government Department of Health |
| Asthma Australia colds and flu campaign | Encourage flu shot and diligent asthma management at the start of winter | Asthma Australia |
| Australian Immunisation Register (AIR) | A national register the records vaccines given to people of all ages in Australia.  Formerly known as the Australian Childhood Immunisation Register but now records vaccines for people of all ages in Australia (since 30 September 2016). | Australian Government Department of Human Services |
| 6th Community Pharmacy Agreement | The Government will provide $825 million over three years, from 2017-18, to community pharmacies to support and improve Australians’ access to medicines, under the Improving Access to Medicines – support for community pharmacies measure. This includes $600 million through the Sixth Community Pharmacy Agreement (6CPA) to continue existing community pharmacy programs and enable pharmacists to deliver new and expanded medication management services for Australians who need additional assistance to manage their medications. | Australian Government |
| National Immunisation Program (NIP) | Free influenza vaccinations every year for   * 6+ months with certain medical risk factors * ATSI children 6 months to <5 years * ATSI peoples 15+ years * 65 years and over * Pregnant women   Haemophilus influenza type b vaccination for babies aged:   * 2 months, 4 months, 6 months, 18 months.   Pneumococcal vaccination available for:   * Children at 2 months, 4 months, 12 months [as well as 6 months if medically at risk] * All those aged 65+ years * ATSI children living in high risk areas (Qld, NT, WA, SA) * ATSI people 15 to 49 years with medical risk factors * ATSI people 50+ years | Australian Government Department of Human Services |

1.5 REDUCE SMOKING RATES

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| iCanQuit calculator | Calculates how much you could save if you quit smoking | Cancer Institute NSW, NSW Govt |
| The National Drug Strategy- Monitoring of smoking rates | The National Drug Strategy Household Survey has collected information about smoking in Australia every 3 years since 1993. | Australian Government Department of Health |
| National Tobacco Campaign  (www.quitnow.info - the Quit Book - ‘Want to quit?’ brochure | The campaign aims to deliver personally relevant information about the health impacts of smoking and importantly, to show smokers the health benefits that quitting has for themselves and their community. A range of tools are available that provide further support for smokers including the Quitline 13 7848 and the My QuitBuddy (An app personalised to help a person quit smoking on their own terms) and Quit for You Quit for Two apps. QuitCoach, QuitMail, QuiteTxt. Quit.org.au  ‘Don’t Make Smokes Your Story’ toolkit is intended to provide organisations with access to materials to help reduce the smoking rate nationally and provide information on the support tools available.   State-based centres are run through the relevant state and territory health departments: Quit Victoria, Quit South Australia, Quit Tasmania, Quit Western Australia, Quit Tasmania, iCanQuit website (NSW), NSW Quitline(13 QUIT)… | Australian Government Department of Health |
| Quitline SA | Provide support services to assist smokers to quit smoking. The Quitline delivers a culturally appropriate smoking cessation support service to meet the needs of smokers from diverse backgrounds in South Australia, including through telephone based and online support services. | Cancer Council SA |
| Quit Smoking Initiatives program (known as “Tackling Smoking” | Provides smoking cessation support services and a social marketing initiative for Aboriginal people in South Australia who smoke. | SA Health via 3 Aboriginal Community Controlled Services |
| State-wide tobacco smoking cessation mass media campaign (SA) | To reduce smoking prevalence in the South Australian population. A tobacco cessation mass media campaign at best practice levels of at least 400 to 700 Target Audience Rating Points to decrease smoking prevalence. | Government of South Australia (SA Health) |
| Tobacco Action Plan 2016-2018 | The Tobacco Action Plan for the Northern Territory is a commitment to the prevention and reduction of tobacco related harm and commits to the National Partnership Agreement on Preventive Health (NPAPH) benchmarks. | Northern Territory Government |
| Tackling Indigenous Smoking (TIS) | The Tackling Indigenous Smoking programme is a targeted activity funded by the Australian Government under the Indigenous Australian's Health Programme to reduce smoking rates among Aboriginal and Torres Strait Islander people. The programme includes grant funding for regional tobacco control activities. | Australian Government Department of Health |
| TSANZ joint Paper on ECigarette use in Australia | A joint position paper is under preparation by TSANZ - to update Australians on the use of electronic cigarettes as nicotine replacement devices (including an update on the advantages and disadvantages of eCig vaping). The panel consists of the experts on eCig (clinical/basic) and smoking cessation. | TSANZ |

1.6 IMPROVE AIR QUALITY

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| AQ app project (unofficial title) | To provide Sydney siders with information on their exposure to traffic related air pollution. To develop a proof of concept for an app to predict traffic related air pollution concentrations on Sydney streets using NO2 as a marker. The current phase is working towards blending data on NO2 to provide real time information on exposures (with the Uni of Sydney's Centre for Translational Data Science). Once this is complete we will aim to make any potential product compatible with the AirRater app produced for Tasmania. | WIMR |
| National Air Quality Standards | The National Environment Protection Measure for Ambient Air Quality (the 'Air NEPM') sets national standards for the six key air pollutants to which most Australians are exposed: carbon monoxide, ozone, sulfur dioxide, nitrogen dioxide, lead and particles. Under the Air NEPM, all Australians have the same level of air quality protection. The Air NEPM requires the jurisdictions to monitor air quality and this helps to identify potential air quality problems. All jurisdictions commenced formal reporting against the Air NEPM standards in 2002. | Australian Government Department of the Environment and Energy |
| National Clean Air Agreement (2015) | Maps out a path for a clean air future for Australia by helping governments prioritise national actions to address air quality issues. | Australian Government |

Priority Area 2 - Increasing awareness and reducing stigma

2.1 RAISE AWARENESS ABOUT LUNG DISEASES

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Asbestos awareness day/week |  |  |
| Australian Centre for Airways disease Monitoring (ACAM) |  |  |
| COPD patient advocates group (CPAG) | To engage people with COPD, carers, or people who have been personally impacted by a family member or friend with COPD in the design and delivering of LFA products and services to raise awareness of COPD (and other lung conditions) and advocate for those affected by these conditions at a local level. | LFA |
| National Asthma and Allergy Network | The Network is a community of people who have asthma, or who live with or care for someone with asthma, and who want to help improve asthma resources and services. The Network will be consulted for ideas and feedback to ensure the patient perspective is included throughout National Asthma Council's projects. | NACA |
| National chronic respiratory monitoring (including advisory group) | To provide core statistics and information on chronic respiratory conditions for policy makers, health service providers, health planners, researchers and the general community | AIHW |
| National cancer data and monitoring on lung cancer | To compile national lung cancer incidence and mortality data, and to monitor lung cancer for policy makers, health service providers and planners, researchers and the general community. | AIHW |
| National PJ Day | Held every winter in support of the 2.5 million Australians living with asthma. | Asthma Australia |
| Public health communication, engagement and education program | Improve awareness, knowledge and preparedness for an epidemic thunderstorm asthma event, and increase community resilience and decrease impacts of a potential event. Improve health professional understanding and management of asthma and hay fever, and thunderstorm asthma. Face to Face health professional education sessions targeting GPs, nurses and pharmacists - online training for health professionals and for community - public health campaign utilising social media, PR, radio to promote health promotion messages around asthma & hay fever management and thunderstorm asthma - development of resources about thunderstorm asthma and asthma first aid in variety of formats and languages, and circulating resources | Department of Health and Human Services, Vic. |
| Sleep Awareness week | To raise awareness in the general population of the importance of sleep health and seeing your GP/Sleep Specialists if you have recurring sleep problems. It focuses on raising awareness of the importance of sleep health and the negative impact of sleep deprivation on overall health, safety, alertness and productivity. | Sleep Health Foundation |
| World asthma day |  | GINA, Asthma Australia |
| World COPD day | Increase community awareness about the symptoms, risk factors and treatment for COPD. | GOLD, LFA |

2.2 REDUCE STIGMA/DISCRIMINATION

This section includes evidence and experience around the impact of stigma.

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| LFA Patient Survey | A survey to gain a deeper understanding of the key issues facing our patient and carer communities, and to see where LFA meets – or can better meet – their needs. | LFA |
| Improving Outcomes for Australians living with Lung Cancer: A call to action (2016) | This report highlights opportunities to change the face of lung cancer in Australia; we can each play our part from practice to policy, from research to implementation, from individuals to organisations. | LFA |

Priority Area 3 - Empowering people to take an active role in their health

3.1 EDUCATE PATIENTS ABOUT THE IMPORTANCE OF SYMPTOMS TO ENCOURAGE TIMELY ACTION AND REDUCE DELAYS IN DIAGNOSIS

This section includes initiatives that are aimed at educating the general public on the importance of lung health, the need to recognise symptoms of lung disease and the need to act promptly. Educating patients and the general public in this way will ensure that medical assessment, where necessary and appropriate, and diagnosis can occur in a timely fashion.

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Asthma Australia consumer brochure series | Series of brochures including basic facts, meds and devices, pregnancy, seniors, asthma & smoking, things to ask your doctor / pharmacist etc. These can be downloaded from the Asthma Australia website, and a range of these are also included in the electronic control packs emailed when people register for Asthma Assist. | Asthma Australia |
| Asthma Clinic Education Service | An outpatient service in tertiary referral hospital to improve the health of people with asthma. | NSW (RPA?) |
| Asthma health promotion campaigns | To encourage people to take actions to ensure their asthma is well managed, or those that they care for. Campaigns include: - **Back to School at the start of the school year**; this reminds people that there is a spike in asthma flare-ups when kids return to school, and provides a checklist and other resources so teachers and parents can ensure children are well prepared when they return to school - **Colds and flu**; encourage flu shot and diligent asthma management at the start of winter - **SABA overuse**; encourage people not to over rely on reliever and educate on the role of preventer vs. reliever in good asthma management - **Flare up**: educate on asthma first aid so you know what to do when you or someone you know has a flare-up - **Asthma and Allergy at the start of spring**; encourage good control of hayfever as part of good asthma management - **Severe Asthma**; promotion of new severe asthma toolkit | Asthma Australia |
| Check in with your lungs | National Awareness Campaign which encourages people to take an interactive online Lung Health Checklist and prompts them to think about their lung health before issues arise. | LFA |
| Cognitive Behavioural Therapy (CBT) Treatment of panic attacks and panic disorders in COPD | This is an ongoing program of clinical research on CBT for prevention and treatment of panic anxiety in COPD/psychological strategies for breathing management in COPD.  There are various challenges to be considered in treating panic spectrum psychopathology in COPD – for example, the problem of ‘controlled breathing’ being a ‘safety seeking behaviour’ in CBT for panic disorder, while COPD’s cardinal symptom – worsening shortness of breath on physical exertion (in the context of an eventually fatal illness) – necessitates attention to managing breathing. Modifications need to be made to standard CBT for panic attacks and panic disorder as a result of the nature of respiratory diseases. | Dr Nicole Livermore, Prince of Wales Hospital, South Eastern Sydney |
| The Find Cancer Early Campaign | To increase awareness of the early signs and symptoms of bowel, lung, prostate and breast cancer in people aged over 40 years living in regional Western Australia. The campaign encourages people to find cancer early and tell their doctor without delay. As well as increasing symptom awareness, the campaign aims to break down some of the barriers and myths to seeking help. Find Cancer Early promotes the message that the earlier cancer is found, the greater the chance of successful treatment. | Cancer Council WA |
| First Aid App | Takes people with asthma, and those supporting people with asthma, through a 4-step asthma first aid process. Enables the user to dial 000 from within the app. Users can practice the asthma first aid steps in a non-emergency situation and hone their skills in assessing if an attack is severe or life-threatening in various scenarios. | Asthma Australia |
| Health Direct Symptom checker | Prompt on asthma page “feeling breathless?” |  |
| Lung health check list | Asks about a range of symptoms, provides information about each and prompts users with appropriate actions to take. | LFA |
| Quality of life checklist |  | LFA |
| Respiratory Conditions Pictorial Flip Charts | Pictorial flip charts were created using plain English to provide education and awareness around acute and chronic respiratory disease for Indigenous families. | Menzies School of Health and Research; Child Health Division |

3.2 PROMOTE SHARED DECISION MAKING

This section explores activities aimed at understanding what is important for individual patients to achieve, reliable patient education on diagnosis, patient stories.

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Aboriginal knowledge, attitudes and perceptions of respiratory illness | To obtain an Aboriginal perspective on respiratory illnesses, health services and programs and to evaluate whether the IROC initiative is achieving its goals of increasing community awareness of respiratory disease. | Menzies School of Health Research |
| Asthma Action Plan survey | To find out who uses these plans, who doesn't, and why. | NACA |
| Getting ready for spirometry fact sheet | Advice for consumers on how to prepare and what to expect when undergoing spirometry testing | NPS MedicineWise, Lung foundation, NAC, AA |
| Health-related quality of life in people with malignant mesothelioma | The project examines health related quality-of-life, unmet care needs and anxiety and depression in people after a diagnosis of MM. It includes a number of optional sub-studies examining associations between these variables and other prognostic indicators such as inflammatory biomarkers, nutritional status and functional status. Site-specific ethics approval was received for 15 participating hospitals and cancer institutions across New South Wales, Queensland, South Australia and Victoria. | ADRI with the Centre for Medical Psychology & Evidence Based Decision Making |
| PEEK study into Lung Cancer | Patient Experience, Expectations and Knowledge (PEEK) is a research program developed by CCDR. The aim of PEEK is to understand the patient experience, expectations and knowledge of lung cancer patients by conducting patient experience studies across lung cancer using a protocol that will allow for comparisons over time (both quantitative and qualitative components). | International Centre for Community Driven Research  Sponsored by AZ |

3.3 SUPPORT DEVELOPMENT AND IMPLEMENTATION OF DECISION TOOLS AND TECHNOLOGY

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Action plans for asthma and COPD |  |  |
| *Bronchiectasis Action Management Plan* | Families of children living with bronchiectasis. Design a personalised written bronchiectasis action management plan to improve clinical outcomes and reduce non-scheduled doctor visits. | Menzies School of Health and Research, Child Health Division |
| Indigenous COPD Action Plan |  | LFA |
| Inhaler technique checklist | A checklist for accurate inhaler technique aimed at health professionals and consumers. | NPS MedicineWise |
| Investigating symptoms of lung cancer: a guide for GPs | This guide was developed to assist GPs to manage people who have or may have lung cancer and support the early and rapid referral into the cancer care pathway. This is a general guide to appropriate practice to be followed subject to the clinician’s judgement in each individual case. | RACGP, Australian Government, Cancer Australia. |

3.4 PROVIDE INFORMATION ABOUT TRIGGERS

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| AirRater App | A free smartphone app designed to support people with asthma, allergies and other respiratory conditions better manage their health. It lets you: - Log your symptoms of hay fever, asthma or allergies in one place - Check the air quality and pollen concentrations at any location (the app shows near real-time readings of smoke, pollen and temperature for the immediate area) - See the location of bushfires and planned burns - Set up saved locations so you can quickly view what is happening in areas you visit frequently. | Menzies Institute for Medical Research, UTAS |
| AQ app project (unofficial title) | To provide Sydney siders with information on their exposure to traffic related air pollution. To develop a proof of concept for an app to predict traffic related air pollution concentrations on Sydney streets using NO2 as a marker. The current phase is working towards blending data on NO2 to provide real time information on exposures (with the Uni of Sydney's Centre for Translational Data Science). Once this is complete we will aim to make any potential product compatible with the AirRater app produced for Tasmania. | WIMR |
| AusPollen | The AusPollen project will provide allergy and asthma patients with accurate, relevant, localised information on pollen counts. AusPollen will lead to reduced symptoms, improved quality of life, and will empower patients to self-manage their condition. | The AusPollen Partnership is a multi-centre cross-disciplinary team of investigators including eminent allergy physicians and scientists. |
| Epidemic thunderstorm asthma (ETSA) forecasting | Vic DHHS contracted Bureau of Meteorology (BoM) to deliver ETSA forecast between 1 Oct to end Dec. Forecast hosted on multiple websites and level determines messaging and preparedness taken on that day. | forecast is generated by BoM but provided to DHHS to release to community |

3.5 PROVIDE PSYCHO-SOCIAL SUPPORT/SOCIAL CONNECTEDNESS ‘YOU ARE NOT ALONE’

This section includes activities for the support of patients with lung disease and their carers/friends.

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| **PATIENT SUPPORT PROGRAMS** |  |  |
| 1800 Helpline (Asthma) | People with asthma  Tailored information and education against the national guidelines on best practice asthma self-management, supporting patients to navigate their treatment plans and working with GPs to share information and optimise care (via phone and in written communication). | Asthma Australia |
| Adolescent Asthma Action (Triple A) Program | Triple A is a proven peer-led education program to improve asthma self-management and discourage uptake of tobacco smoking. Peer education occurs within the school setting and involves senior students delivering a health education program to younger students. The program uses a series of structured lessons, to educate younger peers about asthma, asthma management and how to resist peer pressure towards tobacco smoking. These lessons involve games, activities, videos and a quiz show. | Primary Health Care Education and Research Unit, Research Education Network, Western Sydney Local Health District |
| Asthma clinic | Improve management and outcomes, improve education, and promote independence (age appropriate – mostly under 15s but some adults) in asthma management. Patients can self-refer, but most come via Paediatricians or GPs. | Nurse Practitioner - Leanne Boase Consulting |
| Better Care in the Community – Respiratory service | Provide clients with respiratory conditions (e.g. COPD, asthma) with information about their condition and strategies to improve self-management to reduce avoidable presentations to hospital. Respiratory nurses conduct spirometry, provide inpatient, outpatient and home based services, provide respiratory disease education, care planning and clinical support to clients and work closely with the client’s healthcare team to develop individualised action plans and management plans. | Facilitated through the Better Care in the Community Program across 12 locations in country SA. |
| Better living with Chronic Lung Disease Education Seminars | Provides the opportunity to learn more about lung disease, including topics such as managing your condition, current research and treatment options for patients, carers, their families and friends + interested health professionals. Education seminars are held in different locations throughout Australia. They are presented by volunteer health professionasl and patients on a variety of topics to empower people to be more proactive in their self-management. | LFA |
| Cancer Council support | Coping with Cancer- Speak to a health professional or find a support group  Cancer information and support line 13 11 20 or email  Financial and legal assistance and couselling  Transport, accommodation and home help: practical advice and support during and after treatment  One to one support – talk to someone who has experienced cancer)  Cancer council online community support | Cancer Council |
| CFPhysio.com | Physiotherapists and CF patients. CFPhysio.com is a website designed to empower and enhance individuals with CF and their understanding of physiotherapy management in CF; and to provide physiotherapists with a resource practical and theory based for current evidence based practice in physiotherapy management in cystic fibrosis. The website is still currently being developed and is involving physiotherapists around Australia and New Zealand. | It is being driven by a group of physiotherapists across Australia and New Zealand (Jenny Hauser, Lead Physiotherapist) and being funded through an unrestricted educational grant from Vertex with TSANZ and CFA supporting the venture |
| COACH program | To help people with asthma, or those who care for someone with asthma, improve their general health and asthma control. The COACH Program is a confidential, free health service delivered over the phone by trained Asthma Australia Coaches. The COACH Program - includes regular scheduled calls over a number of months - provides personalised information tailored to the individual’s lifestyle - identifies gaps in treatment and makes recommendations consistent with best practice asthma guidelines - supports people in setting goals - offers regular support - complements GP care | Asthma Australia |
| COPDD and asthma reviews | All adult patients admitted to FMC with COPD/asthma diagnosis are provided with review, education and assistance with inhaler technique. | Respiratory and Sleep service SA |
| COPD Online Patient Education (COPE) | To support patients to self-manage their COPD as an alternative to attending the face to face education component provided in pulmonary rehabilitation programs. | LFA with BUPA (via online platform) |
| Cystic Fibrosis Australia Activities | Little Day Out (SA, Tas), Sibling and offspring activities (SA), Equipment hire, Gym membership and fitness equipment subsidy (Tas), Parent events (Tas), Take a Break Program (Vic), Happy Family Program (Vic), Holiday cabins (Vic), Emergency assistance (Vic), Simon’s adventure fund (Vic), Maya’s Gift (Vic), E-mentoring (WA), counselling, information packs and resources, online school education, CF education, Community education. | CFA and state/territory branches |
| Dust Diseases Care Support Organisation Funding Program | To support people with a dust disease and their families  The Support Organisation Funding program offers grants for not-for-profit, charity groups or organisations that provide support to people with a dust disease and their families. The grants are available to organisations that inform, educate and support people with dust diseases and their families, and optimise the wellbeing of people with a dust disease. | icare NSW Dust Diseases Care |
| Face to face Lung Cancer support group | A monthly face to face facilitated meeting for lung cancer patients and carers. Some meetings include a formal topic with guest speaker. | Lung cancer support nurse and GM Thoracic cancers of Lung Foundation Australia |
| First Aid for Asthma | Provides instructions on what to do if a person is having an ‘asthma attack’ | NACA |
| Information and support line 1800654302 | To provide up to date information, education, support and referral for people impacted by all lung diseases. | LFA |
| Interstitial Lung Disease Education Course | To educate and empower patients and carers with ILD (mostly sourced from RPA ILD Clinic). Patients attend lecture-based classes of 2-hour duration over 6 weeks on subjects ranging from diagnosis, treatment, management of comorbidities, pulmonary rehabilitation and maximising quality of life. | RPAH ILD Clinic |
| Interstitial Lung Disease Patient Education Course at Australian Rare Lung Disease Short Course | To educate patients on all aspects of ILD. The half-day course aims to educate patients and their support people about all aspects of their care, from diagnosis though treatment and monitoring including pulmonary rehabilitation and maximising quality of life. Program is taught by specialist nurses along with invited international speakers, expert psychologist and physiotherapist. Patients travel from all over Australia to attend this event. | ARLDSC is sponsored by TSANZ and Lung Foundation Australia with industry support |
| JAM – Just Asthma Messages | A free text messaging services designed to provide people with asthma with the information and skills to manage their asthma well. Over 4 weeks, participants receive 13 text messages on key asthma management topics e.g. the importance of using a spacer, why you should take a preventer, and what to do in an asthma emergency. | Asthma Australia |
| Lung cancer telephone support nurse | A telephone service to support those with lung cancer navigate the health system, with their psychosocial needs, education needs via facilitated shared experience. | LFA  Lung cancer support nurse and GM thoracic cancers of LFA |
| Lung Focus Support Group | Provide a monthly forum for clients with lung disease to come together for peer support and further education regarding their condition. | Peer led support group supported from the local health service. CHSALHN |
| Mesothelioma Support | The different groups of patients are those newly diagnosed and wanting clinical information and empathetic support; patients in a stable condition, who want to live a ‘normal’ life as much as possible; and patients with progressive (symptomatic) disease with complex medical and psychological needs. The support coordinators also support carers and families of mesothelioma patients and the bereaved who have lost a loved one to mesothelioma. | Asbestos Diseases Research Institute (ADRI) |
| MDT speciality Care | To educate and empower young adults with CF to self-manage a complex and chronic disease. Outpatient clinics, Inpatient treatments, Education, Skills training, Psycho social support, Monitoring health status, Empowering self-management, Facilitating access to various associated health care professionals. | Cystic Fibrosis specialist services at WMH adults  (rnig) |
| Patient support group | People and their carers living with chronic respiratory disease. Patient support group run as per LFA patient support guidelines | Physio support, patient-led committee NSW |
| Pulmonary Fibrosis Peer Connect Service | To provide patients and carers who are impacted by pulmonary fibrosis with the opportunity to connect with another person in a similar situation for mutual support and sharing of lived experiences. | Rare Lung Disease Manager & Information & Support staff, LFA |
| Rare Lung Disease Webinars | To provide up to date education and support for people with rare lung disease. Online webinars for people living with pulmonary hypertension and pulmonary fibrosis are offered 3 times a year with the recording being uploaded to the LFA website. The webinars are presented by volunteer clinicians and patients. There is no cost to attend and bookings are taken through an online form for health professionals and via the information and support information line. | Rare Lung Disease Manager, LFA |
| Respiratory nurse led clinics | For patients with asthma, COPD, ILD, bronchiectasis to promote patient self-management, and slow disease progression.  Respiratory nurse led clinics. Respiratory assessment. +/- spirometry Condition and management education. Inhaler device technique. Linkages - e.g link to pulmonary rehabilitation, and other services as needed. Address/review: incontinence, HACC, ACAT, advanced care planning. Liaise with GP, respiratory physician as needed. | Black Swan Health |
| Structured home-based education (COPD) | Aimed at people with COPD who attend hospital to improve the client’s capacity for self-management. Registered nurses attend the client's home and provide education based on the COPDx guidelines in the form of 6 structured modules. Staff are trained in motivational interviewing. They also monitor the health of the clients and medical staff provide outreach to address any identified deterioration early and clinically manage their condition. | The Hospital Admission Risk Program (the Alfred) |
| **APP DEVELOPMENT FOR SELF-MANAGEMENT** |  |  |
| AirRater App | See also *1.6 Air Quality* for a description of the AirRater app | Menzies Institute for Medical Research, UTAS |
| Asthma app | The app includes: - Information about what is asthma - Medications - particularly preventer and reliever screens - Delivery device instructional videos and information. | Asthma Australia |
| CFBuzz App | CFBuzz is an app built specifically for adults with cystic fibrosis and helps assist in CF self-management. It offers the ability to record personal health information, monitor progress against goals and keep track of all your contacts and appointments. CFBuzz was built from the ground up with consultations from both the cystic fibrosis community and leading medical professionals. | CFA |
| Kiss My Asthma App | Aimed at young people 12-25 years, and anyone else with asthma, to support people in better managing their asthma. The app features: - access to your Asthma Action Plan - tracking symptoms, attacks and mood, - setting goals – medication reminders - Asthma First Aid instructions and emergency contacts - information about medications and devices, and managing anxiety | Asthma Australia |
| Lung App | Education and awareness of how to manage acute or chronic lung disease in Indigenous families of children with lung disease. | Menzies School of Health and Research |
| **CREDIBLE INFORMATION SOURCES** |  |  |
| Asthma Australia | Various ‘how to’ videos, information sheets and resources….  What is asthma? Diagnosing asthma. Triggers. How is asthma managed? Medicines and treatment. Using your medicines correctly. Useful links. FAQ.  Asthma action plans, education and training, spirometry training and tools, print resources. |  |
| Cancer Council | Printable resources: Understanding lung cancer, Caring for someone with lung cancer, Understanding mesothelioma. Guides and factsheets for people with cancer, their families and friends.  Cancer council information service |  |
| Cystic Fibrosis Australia | What is CF? Who gets CF? How is CF treated? How is it diagnosed? Carrier screening |  |
| Dust Diseases | DDC clients or current workers icare NSW Dust Diseases Care has published several brochures and factsheets on its website aimed at assisting those people who may have been exposed to hazardous dust, or those with a compensable dust disease. Our resources range from medical examination factsheets through to dust disease brochures, as well as information on how to apply for compensation for a dust disease. | icare NSW Dust Diseases Care |
| Lung Foundation Australia | Living with a lung condition, Lung information and patient support, information and support centre, patient education resources, LungNet Newsletter….. |  |
| National Asthma Council Australia instructional videos | Various ‘how to’ videos and information sheets **Inhaler technique videos**: How to use Accuhaler, How to use Ellipta, How to use HandiHaler, How to use a standard MDI (puffer), How to use a standard MDI (puffer) and Spacer, How to use a Puffer and Spacer for Kids, Respimat (loading before first use), How to use Respimat, How to use Rapihaler with Spacer, How to use Autohaler, How to use Turbuhaler, How to use Rapihaler, How to use Breezhaler, How to use Genuair, How to use Flutiform, How to use Flutiform with spacer, How to use Cipla inhaler, How to use Cipla with a spacer, How to use DuoResp Spiromax.  **More videos**: Performing spirometry in primary care, Is it an asthma emergency?, Finding the right asthma information, How your pharmacist can help, Asthma action plans are a must, When should your child see a specialist?  **Information**: Understanding asthma, Living with Asthma, Asthma First Aid | NACA |
| Pulmonary Hypertension Association Australia | Explaining PH, Diagnosis, Current medications, glossary of terms, classification of PH…. |  |
| Sleep Health Foundation | Various sleep health fact sheets: Common sleep disorders, understanding and helping poor sleep, sleep apnoea, caring for your CPAP equipment, CPAP, CPAP – making it work for you, surgery for obstructive sleep apnoea…. |  |

Priority Area 4 - Promoting Equitable Access to Evidence-Based Care

## [Primary Health Networks](http://www.health.gov.au/internet/main/publishing.nsf/Content/PHN-Home)

Across Australia, On 1 July 2015, 31 PHNs were established to increase the efficiency and effectiveness of medical services for patients, particularly those at risk of poor health outcomes, and to improve coordination of care to ensure patients receive the right care in the right place at the right time. PHNs will achieve these objectives by working directly with general practitioners, other primary health care providers, secondary care providers and hospitals to facilitate improved outcomes for patients.

The Government has agreed to seven key priorities for targeted work by PHNs. These are mental health, Aboriginal and Torres Strait Islander health, population health, health workforce, digital health, aged care, and alcohol and other drugs. At this stage, lung disease doesn’t appear to be a key priority for targeted work by PHNs, but in addition to these key priorities, the PHNs are encouraged to address their own local needs.

A distinguishing feature of Primary Health Networks (PHNs) is that they will adopt a commissioning approach to procuring medical and health care services. The PHN Commissioning - Needs Assessment Guide has been developed by the Department of Health to support PHNs in planning and undertaking a needs assessment process that will identify and analyse health and service needs within their regions and prioritise activity to address those needs. The guide provides an overview of the PHN commissioning framework and discusses the key elements of needs assessment, including the steps involved in conducting health needs analysis and service needs analysis, synthesising the evidence, and determining priorities and options.

Within this stocktake there are activities listed as being undertaken by PHNs. We have been reliant upon contributions from PHNs so it is difficult to know the extent to which the 31 PHNs have commissioned medical and health care services related to lung disease. However, opportunities exist to leverage information from PHN needs analyses.

4.1 FACILITATE EVIDENCE-BASED DIAGNOSTIC TESTING

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Provision of Ambulatory Sleep Studies in rural and remote SA | Conduct an assessment in people at risk of Obstructive Sleep Apnoea or Central Sleep Apnoea to determine whether the client has sleep apnoea and the severity of this condition. Clients attends appointment with a Respiratory Nurse at one of three CHSA health units. The nurse conducts an assessment, provides education and fits the equipment for the client. The client sleeps at home and returns the equipment the next day. Data from the equipment is downloaded and sent to a Respiratory Physician for interpretation and review for further treatment. | Respiratory nurses in country SA and visiting respiratory physician services from Royal Adelaide Hospital |
| AREST CF – Preschool Lung Function testing | To detect and monitor the onset and progression of early cystic fibrosis children perform multiple breath washout and complete symptom Q’aires at clinical review appointment, at annual review and at admission and discharge to hospital for a respiratory exacerbation. | AREST CF, Telethon Kids Institute |
| Free lung disease examination for former coal workers |  | Workcover Queensland |
| Indigenous Respiratory Reference Values Study | To develop valid reference values for Indigenous Australians for 2 commonly utilised respiratory function tests - spirometry and fractional exhaled nitric oxide. Currently there are no published valid Australian Indigenous reference values for spirometry, without which the utility of the test is limited for Indigenous Australians. > 1100 healthy Aboriginal children and young adults (ages 3-25years) in 8 Queensland communities have been tested, enabling the publishing of healthy reference ranges for paediatric spirometry. Adults are now the focus. | Prof Anne Chang and Dr Margaret McElrea |
| International Lung Screen Trial | An international study aiming to understand the best way of choosing high-risk people for lung cancer screening as well as a way of following up with repeat CT scans.  There are a number of sub-studies from ILST, including one in WA examining the best way to recruit people into a lung cancer screening program. | Australian centres in Brisbane (where the study is based), Sydney, Melbourne and Perth. |
| Lung function testing unit – Whyalla | People at risk of Obstructive Sleep Apnoea or Central Sleep Apnoea. Priority is given to Health Care Card holders. Assessments are conducted to determine whether the client has sleep apnoea and the severity of this condition. Pulmonary Function Testing (PFT) Analysis system. This system enables comprehensive PFT on location in Whyalla inclusive of Body Plethysmography, Spirometry, Lung Diffusion Capacity, Radiology Imaging and Blood Gas Analysis. | Respiratory Nurses in collaboration with technicians and Respiratory Physician services from Royal Adelaide Hospital |
| Pulmonary Assessment Clinic | Assess, diagnose and manage patients with chronic lung disease (all comers) who require upcoming surgery or sedation as part of an upcoming procedure. The aim is to assess medical fitness and reduce complications post-procedure. | Dr Chin Goh & Dr Vicky Chang, Part of Sutherland Hospital outpatient clinic. |
| Respiratory Failure and Airways Clinics | Assess, diagnose and manage patients with chronic respiratory failure and COPD. Outpatient weekly clinic for follow up of hospital admitted patients with acute or chronic respiratory failure. Arrange oxygen and/or NIV long term as part of management. Assessment of new patients with borderline respiratory failure. Assess COPD patients. | Dr Con Archis and Dr Clarissa Susanto |
| Sleep Clinic | Assess, diagnose and manage patients with sleep disorders. Review of all patients with potential sleep disordered breathing referred from the hospital or community. | Dr Ben Kwan & Dr Andrew Ng, Part of Sutherland Hospital outpatient clinic. |

4.2 PROMOTE RAPID REFERRAL WHERE NEEDED

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| CF Carrier Screening | CF carrier screening services are available in Australia to help you find out whether you or your partner carry the CF gene change. CF screening involves providing a blood or saliva sample and requires a referral from your GP, Obstetrician or Gynaecologist. There are over a thousand gene changes that cause CF. A typical CF screening request will identify the most common CF gene changes in Australia. | CFA |
| Rapid access clinic – Lung Cancer and Pleural focus | To facilitate prompt and accurate assessment and diagnosis of patients with suspected to have lung cancer and pleural effusion. Patients get information before and after the procedure. This also facilitates the lung cancer MDT which ensures quality care is delivered to every patient with a diagnosis of lung cancer in SALHN. The clinic is conducted by a dedicated group of specialists with a focus on lung cancer, a level 3 nurse and a specialist registrar. | SALHN respiratory  (Flinders Medical Centre and national) |
| Respiratory Procedure/ Lung cancer and Pleural | To facilitate prompt and accurate diagnosis of patients with suspected lung cancer and interstitial lung disease and other disorders who need an intervention. The diagnostic procedures include - Bronchoscopy, Transbronchial lung biopsy, Endo Bronchial Ultrasound, Cryobiopsies, Tunnelled Indwelling Pleural Catheter Insertion.  The procedural aspect of respiratory medicine is handled by a core group of clinicians who do highend diagnostics. The HOPE programme (the HOme Pleural Effusion Programme), facilitates outpatient management of pleural effusion. | SALHN |
| ILD service | To optimise the care of patients with ILD (including new referrals and cross-referrals from other specialists for new and existing patients) through implementation of current best practice guidelines and evidence. | SALHN Respiratory and Sleep services |
| Providing education and support on self-management of chronic disease to prevent unnecessary hospital admissions | Aimed at patients with chronic lung disease or possible undiagnosed lung disease who present in hospital. Link with an outreach respiratory clinical nurse consultant for education and support on self-management - includes inhaler techniques, assessment and regular reviews on home visits, breathing/airway clearance techniques, education on pathophysiology of disease. Provide a link to a respiratory physician, lung function test if needed. Implementation of action plan to prevent exacerbations. Link to pulmonary rehabilitation program. Link to community support services as required. | Complex Care Program in Monash Health |

4.3 PROVIDE EQUITABLE ACCESS TO SPECIALIST CARE, WHERE NEEDED

In most hospitals, there are hospital-based services specifically for CF, asthma, COPD, bronchiectasis, ILD, pulmonary hypertension, lung cancer, sleep disorders, allergy, occupational lung disease etc. This section includes activities targeted at those in remote areas, or provision of specialist services in the home.

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Airway clearance (physio) & exercise support by home care workers | Children and adults with CF. Home care workers provide in home support to assist parents and adults develop good routines around airway clearance and exercise to shift mucus from the lungs. This program also delivers respite and light home duties to provide emotional support in times of need. | Cystic Fibrosis WA |
| Ambulatory monitoring of subjects with COPD | Subjects with COPD recruited from (i) specialist services and (ii) General Practices to test feasibility and acceptability of ambulatory monitoring of COPD.  A preliminary study to develop a mature intervention (tools and protocols) to enable and guide the study design of a prospective, adequately powered, RCT to assess whether telemonitoring for COPD patients at risk of exacerbations can lead to better healthcare outcomes, reduced number of hospital admissions and shorter length of stay. | Celler, Jenkins, Marks, Peiris, Siaw-Teng Liaw, Argha (SPHERE) |
| Certified suppliers of CPAP Therapies | A list of certified suppliers of CPAP therapies in Australia | Sleep Health Foundation |
| Home oxygen service | To provide education and follow-up for patients receiving SA Health funded home O2 equipment. Nurses arrange provision of home O2 to patients prescribed O2 within the SALHN catchment area. This includes liaison with O2 companies and families to ensure equipment is appropriate. Regular home visits are undertaken in the first year of receiving Home O2 to check on the safety of the equipment and the patient. Thereafter, patients are offered a hotline service to the respiratory nurses for trouble-shooting any of the issues and hospital avoidance if needed. | Respiratory and Sleep Services SALHN |
| Home ventilation service | Provision of home ventilation (CPAP, NIV), including masks and other related equipment, for patients with sleep disordered breathing and/or respiratory failure within the SAHLN catchment or Country SA who fulfil specific criteria (e.g. Healthcare Card or Pensioner Concession Card holders; moderate-severe OSA by apnea hypopnea index; excessive daytime sleepiness; cardiovascular disease risk factors, etc). | Respiratory and sleep services, SA. |
| Indigenous Respiratory Outreach Care (IROC) Program | Provide specialist services in rural and remote Indigenous communities in Queensland. Improve lung health in rural and remote Indigenous communities.  IROC staff coordinate with specialist staff to plan and implement outreach clinics. IROC staff also liaise and negotiate with rural and remote communities and staff to provide sites for the clinics. There is an Adult team and Paediatric team who visit the communities. Teams consist of respiratory physician, respiratory nurse, scientist, physiotherapist (paediatric team only) and project officers. Staff are sourced from a variety of HHS's across Qld. Note: This is one example of the activities funded under the ‘National Partnership Agreement on Closing the Gap in Indigenous Health Outcomes’. | The program is hosted by Metro North Hospital and Health Service, The Prince Charles Hospital. |
| Lung Cancer Chemotherapy Services | Minimise travel for clients requiring chemotherapy who reside in country South Australia. Provide services closer to home. Chemotherapy services are provided at 15 sites across country South Australia. | Chemotherapy nurses and visiting oncology services. CHSALHN |
| Lung cancer multidisciplinary teams (MDT) | A range of models are implemented for multidisciplinary management of patients with lung cancer. | Various health services across Australia |
| Lung cancer MDT directory | A directory of multidisciplinary teams for lung cancer across Australia is available from the LFA here: https://lungfoundation.com.au/mdt/ | LFA |
| Medical Outreach Indigenous Chronic Disease | The Medical Outreach Indigenous Chronic Disease Program improves access to health services for Aboriginal and Torres Strait Islander people with chronic disease, with a focus on rural and remote locations. The program funds multi-disciplinary outreach services, including medical specialists, general practitioners and allied health professionals. Funding is managed by jurisdictional fundholders. Many of the services are delivered through Aboriginal Community Controlled Health Services. | Australian Government Department of Health  Fundholders: NSW – Rural Doctors Network, NT – Northern Territory, Primary Health Network, QLD – CheckUP, SA – Rural Doctors Workforce Agency, TAS – Tasmanian Department of Health and Human Services, VIC – Rural Workforce Agency Victoria, WA – Rural Health West. |
| Outreach services | Aboriginal communities | ACCHO |
| Pulmonary Rehabilitation Services | A diverse range of models exist (hospital-based, community-based, home-based).  All involve exercise. Most provide psychosocial support | Various health services. |
| Pulmonary rehabilitation Map/ Lungs in Action Map | The map includes:   * Exact location and access details * Referral criteria and instructions * Program delivery details such as day/times and length of program * Program contact details   https://www.google.com/maps/d/viewer?mid=1knWFOcM17tOSN36nvmn2C4q1QML3ke8R&ll=-26.8006362906408%2C138.5781868125&z=6 | LFA |
| Pulmonary rehabilitation toolkit | The Pulmonary Rehabilitation toolkit is a resource for health professionals to design and deliver an evidence-based Pulmonary Rehabilitation program to benefit people managing lung disease. https://pulmonaryrehab.com.au/ | LFA |
| Respiratory assessment and pulmonary rehab | Home visits and clinic visits to confirm diagnosis, carry out lung function, assess patient’s condition and provide a comprehensive package of care to improve their exercise tolerance and self-management skills. | Qld |
| TB clinics | Diagnosis and management of people with TB and public health actions to control TB are organised by the state/territory, with different organisation (e.g. centralised or area/district health services) | State/territory health departments |
| WCHN Respiratory inpatient/outpatient clinic | Care for children with severe asthma, complicated pneumonia, sleep disordered breathing, chronic lung disease, etc. | WCHN, Tas. |
| Women’s and Children’s CF inpatient/outpatient care | The WCHN is the central site for care of children with CF in South Australia. The aim of this clinic is to optimise the lung function, nutrition and quality of life of children with CF. As an extension of this service the Hospital-in-the-Home service provides care for children with CF and like conditions to undergo treatment at home. | Women’s and Children’s Health Network (WCHN) Tas |

4.4 PROMOTE ADHERENCE TO EVIDENCE-BASED CARE AND REDUCE VARIATION IN CARE

This section includes information about decision support tools, clinical guidelines, integrated care or models of care.

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| **INTEGRATED CARE/MODEL OF CARE** | | |
| Aboriginal Respiratory Care | To improve the cultural capability of the education and disease management for Aboriginal people with chronic lung disease by developing a program and learning map based on the 8 ways of learning, delivery of the program to aboriginal health workers, evaluation, ongoing planning for programming at local sites. | ACI |
| Asthma management: elements for good control pharmacy practice review | To support pharmacists with asthma management by exploring the elements for good control. | NPS MedicineWise |
| Asthma: optimising asthma control in children | An online case study aimed at health professionals to: select age-appropriate preventer medicines and devices, make treatment recommendations based on asthma classification, promote use of written asthma action plans to help patients better manage their asthma, and implement a systems approach to monitor patients' asthma control. | NPS MedicineWise |
| Atlas of Healthcare Variation | There have been 2 issues of the Atlas, 2015 and 2017. They illuminate variation by mapping use of health care according to where people live.  As well, the Atlas identifies specific achievable actions for exploration and quality improvement. | The Australian Commission on Safety and Quality in Health Care |
| Bronchiectasis Toolbox | The Bronchiectasis Toolbox is a multidisciplinary resource for the diagnosis and management of people with bronchiectasis. The content, based on national and international guidelines, is designed to provide guidance for health professionals who are providing care to children or adults with bronchiectasis. | Endorsed by TSANZ |
| COPD | Web content which provides best-practice information on COPD for health professionals | NPS MedicineWise |
| COPD: A stepwise approach | A free quality improvement activity that help GPs review their current prescribing practice and overall management for patients with COPD, compared with current best practice guidelines. This Clinical e-Audit guides GPs to: review their approach to using spirometry to diagnose COPD, tailor COPD treatment to maximise control of a patient’s symptoms, identify patient-specific factors that can influence the choice of inhaler device, assess adherence and inhaler technique, and access tools and information for patients. | NPS MedicineWise |
| COPD collaborative | To support earlier diagnosis and improved management of patients with COPD within the general practice setting.  COPD Collaborative is a quality improvement approach using the Model for Improvement framework to develop, test and implement small manageable changes to improve practice system processes. This promotes rapid change, allowing health services to experience the benefits of changes and create results in short time frames. | Nepean Blue Mountains Primary Health Network |
| COPD: demonstrating devices, evaluating medicines pharmacy practice review | To update pharmacists’ knowledge about the stepwise approach to managing COPD and review the range of medicines and devices currently used to treat COPD. | NPS MedicineWise |
| COPD Hub | Aimed at people with COPD, respiratory physicians, GPs, other primary care physicians to improve the delivery of care for patients, with, or at risk of developing COPD to manage their condition in the WA community. | WA Primary Health Alliance |
| COPD: navigating inhaled medicines management | Provides education to GPs, nurses and pharmacists on inhaled medicines and devices for COPD. There are more than a dozen different inhaled medicines for COPD and multiple devices. This case study helps HCP optimise patients’ use of these medicines. | NPS MedicineWise |
| GP education on COPD | To improve the care of patients with COPD. Includes a mix of full day sessions covering COPDX and lunch time sessions covering spirometry, inhaler medication devices etc. | Respiratory Medicine Westmead Hospital |
| Integrated care for COPD | Patient education, disease understanding, puffer technique, smoking cessation, vaccinations, COPD action plan, exercise, pulmonary rehabilitation, address other important medical issues, providing support. | Medical Staff and a senior nurse |
| Integrated care for COPD – GP/Physiotherapist partnership model of care | To investigate whether physiotherapists and GPs working together can improve the care of people with COPD in the community by helping to find patients who have COPD and improving the management of COPD. | A/Prof Zoe McKeough and A/Prof Sarah Dennis |
| Interstitial Lung Disease Toolkit | This toolkit contains material designed to aid in the presentation and discussion of cases presented at interstitial lung disease multi-disciplinary meetings. Content can be downloaded and saved for local use or used as an example to aid in the preparation of individualised templates. | LFA and developed by ILD CRE |
| Leading Better Value Care (COPD) | To improve the value of care and reduce unwarranted clinical variation in the care that patients with COPD receive across the health care continuum. (Audit, feedback, further diagnostics and priority identification, improvement planning, evaluation including re-audit) | NSW Ministry of Health and ACI |
| Lung cancer audit | To assess whether internal medical staff meet the national optimal care pathway for patients that present at the lung cancer MDM. Assess time between GP referral and treatment commencement (should be < 42 days) to identify at a local level where the barriers and delays are to achieving this consistently. This information is reported back to the chair of lung cancer MDM and discussed with individual teams if any quality improvements can be made. | Run by Mel Laan- Lung Cancer Nurse Consultant for Cancer Services |
| National Prescribing Curriculum: COPD exacerbation | An online national prescribing curriculum module aimed at health professionals to improve management of patients with COPD | NPS MedicineWise |
| Nurse Practitioner -respiratory clinics | Role involves a Shared Care model working with GPs and Respiratory Physicians across the Murrumbidgee Local Health District to provide: -Confirmation of diagnosis -Treatment and prevention of exacerbations -Monitor treatment -Referral criteria includes ‘Mod/Severe or End Stage COPD’ ‘Mild/Moderate COPD + co morbidities’ - Smoking cessation associated with chronic disease - Interstitial Lung Disease -Severe Asthma -High risk of readmission due to deterioration or social situation. | Clinics currently run in Wagga Wagga and outreach across the district by running clinics in outlying towns, supported by telehealth. |
| Optimal Care Pathway for people with lung cancer (Assist with the state-wide adoption) | Engaging with people who provide care to patients with a diagnosis of lung cancer. The optimal cancer care pathway is intended to guide the delivery of consistent, safe, high quality and evidence-based care for people with lung cancer. It can be used by health services and professionals as a tool to identify gaps in current cancer services and inform quality improvement initiatives across all aspects of the care pathway.  Assisting in identifying any gaps in current practice the cancer services may have with lung cancer patients. | South Australian Cancer Service (SACS) |
| Respiratory Coordinated Care Program (RCCP) | Provide specialist respiratory nursing and physiotherapy care to adults with chronic lung disease in the community to promote self-management and empowerment, improve quality of life, and reduce unnecessary admissions to hospital. It is a 6-day service. Management includes education regarding lung disease and medications, utilising action plans, collaborating with appropriate medical personnel and health professions to provide optimal holistic care, providing chest physiotherapy, exercise training and home-based pulmonary rehabilitation. RCCP physiotherapist also provides outpatient chest physiotherapy service to adults referred with respiratory impairments. | RCCP CNC |
| Respiratory Integrated Care Service | This is a community-based model with the service delivering advanced and extended respiratory nursing services that interface, integrate and partner other services in the acute and community sectors. The case management of COPD patients aims to avoid hospital admissions and where admission is unavoidable, reduce the length of stay of these patients. The Respiratory Integrated Care Service also provides consults for patients at the request of the medical team or other community providers. This service visits patients in the community in order to further assess and assist in the ongoing management of the patient. | SA |
| The Severe Asthma Toolkit | The Severe Asthma Toolkit (https://toolkit.severeasthma.org.au) is an independent and contemporary online education and training resource that provides clinicians with information and resources relevant to severe asthma. The Toolkit is organised into modules which provide information on: What is Severe Asthma?, Diagnosis & Assessment, Management, Medications, Co-Morbidities, Living with Severe Asthma, Establishing a Clinic, Paediatrics & Adolescents and Resources. | The project is co-led by project leaders Profs. McDonald & Gibson. The Toolkit was developed by a team of multidisciplinary clinicians from Australia & overseas with input from an independent reference group. |
| Standards for the delivery of spirometry for coal miner workers (July 2017) | This document outlines the minimum standards required for performing spirometry for the assessment and monitoring of coal mine workers lung function. https://www.dnrm.qld.gov.au/\_\_data/assets/pdf\_file/0003/1274421/tsanz-spirometry-standards.pdf | Qld Government and TSANZ |
| TSANZ Spirometry Operator Logbook | https://www.thoracic.org.au/educationcourseevents/logbooks | TSANZ |
| Unlocking asthma inhaler technique | An online course to improve asthma inhaler technique | NPS MedicineWise |
| Venturewise Academic Detailing | To educate GPs about COPDX guidelines. GSK provided an independent unrestricted education grant to Venturewise (NPS subsidiary) to deliver independent medical education to GPs about COPDX. | GSK (no involvement with the program design/content etc except for funding of program) |

4.4 Promote adherence to evidence-based care and reduce variation in care - CLINICAL GUIDELINES

| **Name** | **Target audience** | **Produced by** |
| --- | --- | --- |
| **ACUTE ANAPHYLAXIS** |  |  |
| **ASCIA Guidelines – Acute management of anaphylaxis** (2017) https://allergy.org.au/images/stories/pospapers/ASCIA\_Guidelines\_Acute\_Management\_Anaphylaxis\_2017\_Updated.pdf | Medical practitioners and nurses providing first responder emergency care | ASCIA |
| **ASTHMA** |  |  |
| **Australian Asthma Handbook** (2017) http://www.asthmahandbook.org.au/ | Aboriginal Health Care Workers, GPs, nurses, pharmacists | NACA |
| **Global Initiative for Asthma (GINA)** (2018) https://ginasthma.org/2018-gina-report-global-strategy-for-asthma-management-and-prevention/ | Health Care Professionals, Public Health officials, patients and advocacy groups | National Heart, Lung and Blood Institute, National Institutes of Health, USA and the World Health Organisation |
| **Management of acute asthma in children** (2013) https://www.sahealth.sa.gov.au/wps/wcm/connect/8169868040d035a79695be40b897efc8/Management+of+Acute+Asthma+in+Children\_Aug2013.pdf?MOD=AJPERES&CACHEID=ROOTWORKSPACE-8169868040d035a79695be40b897efc8-lNpMU-m | Allied health professionals, GPs, medical specialists, midwives, nurses, paramedics | SA Health |
| **International ERS/ATS guidelines on definition, evaluation and treatment of severe asthma** (2014)https://www.thoracic.org/statements/resources/allergy-asthma/Severe-Asthma-CPG-ERJ.pdf | Medical professionals | ERS/ATS |
| **BRONCHIECTASIS** |  |  |
| **Bronchiectasis position statement** (2010) https://lungfoundation.com.au/wp-content/uploads/2013/12/Position-statement-on-Bronchiectasis-from-TSANZ-and-ALF.pdf | Medical professionals | Thoracic Society of Australia and New Zealand and Lung Foundation Australia |
| **Management of bronchiectasis and CSLD in Indigenous children and adults from rural and remote Australian communities** (2008) https://www.mja.com.au/journal/2008/189/7/management-bronchiectasis-and-chronic-suppurative-lung-disease-indigenous | Medical Professionals – respiratory specialists, paediatricians | Consensus group comprised 37 representatives from Aboriginal-controlled community health organisations, remote health services, medical schools, research institutes and primary, secondary and tertiary health centres |
| **Chronic suppurative lung disease and bronchiectasis in children and adults in Australia and New Zealand** (2015) https://www.mja.com.au/journal/2015/202/1/chronic-suppurative-lung-disease-and-bronchiectasis-children-and-adults | GPs | TSANZ |
| **COPD** |  |  |
| **COPD-X Plan** (2018) https://copdx.org.au/wp-content/uploads/2018/08/COPDX-V2-54-June-2018.pdf | GPs, nurses and the general practice team | Thoracic Society of Australia and New Zealand and Lung Foundation Australia |
| **COPD-X Concise Guide for Primary Care** (2017) https://lungfoundation.com.au/wp-content/uploads/2014/11/LFA-COPD-X-doc\_FINAL-190917.pdf | GPs, nurses and the general practice team | Thoracic Society of Australia and New Zealand and Lung Foundation Australia |
| **Australia and New Zealand Pulmonary Rehabilitation Guidelines** (2017) https://lungfoundation.com.au/wp-content/uploads/2017/03/LFATSANZ-PulmonaryRehabGuidelines-Feb2017-final-edit.pdf | Clinicians, exercise physiologists, medical specialists, nurses, occupational therapists, physiotherapists | Thoracic Society of Australia and New Zealand and Lung Foundation Australia |
| **GOLD Global strategy for the diagnosis, management, and prevention of chronic obstructive pulmonary disease** (2018 report) https://goldcopd.org/wp-content/uploads/2017/11/GOLD-2018-v6.0-FINAL-revised-20-Nov\_WMS.pdf | Healthcare professionals | GOLD Global Initiative for Chronic Obstructive Lung Disease |
| **Management of COPD exacerbations: a European Respiratory Society/American Thoracic Society guideline (2017)** https://www.thoracic.org/statements/resources/copd/mgmt-of-COPD-exacerbations.pdf |  | ERS/ATS |
| **CYSTIC FIBROSIS** |  |  |
| **Cystic Fibrosis: Guidelines For Management – SCH** http://www.schn.health.nsw.gov.au/\_policies/pdf/2015-7018.pdf | Hospital Health Care Professional | Sydney Children’s Hospital |
| **MELBOURNE Handbook for the Management of Children with Cystic Fibrosis** https://www.rch.org.au/uploadedFiles/Main/Content/RESPMED/handbook.pdf | Hospital Health Care Professionals | The Royal Children’s Hospital Melbourne |
| **Nutrition guidelines for cystic fibrosis in Australia and New Zealand** (2017) https://www.clinicalguidelines.gov.au/portal/2584/nutrition-guidelines-cystic-fibrosis-australia-and-new-zealand | Allied health professionals, clinicians and dieticians | TSANZ |
| **INDUCIBLE LARNGEAL OBSTRUCTION** |  |  |
| **Inducible laryngeal obstruction: an official joint European Respiratory Society and European Laryngological Society statement** (2017) http://erj.ersjournals.com/content/50/3/1602221 | Health Care Professionals | European Respiratory Society and European Laryngological Society |
| **INTERSTITIAL LUNG DISEASES** |  |  |
| **Treatment of idiopathic pulmonary fibrosis in Australia and New Zealand** (2017) https://onlinelibrary.wiley.com/doi/full/10.1111/resp.13146?regionCode=AU-QLD&identityKey=fd5dd8c3-8891-4c27-815d-76985ddbda54&wol1URL=%2Fdoi%2F10.1111%2Fresp.13146%2Ffull | Health Care Professionals | Thoracic Society of Australia and New Zealand and Lung Foundation Australia |
| **The ILD multidisciplinary meeting position statement** (2017) https://onlinelibrary.wiley.com/doi/full/10.1111/resp.13163 | Medical professionals | Thoracic Society of Australia and New Zealand and Lung Foundation Australia |
| **An Ofﬁcial ATS/ERS/JRS/ALAT Clinical Practice Guideline: Treatment of Idiopathic Pulmonary Fibrosis** (2015)http://www.thoracic.org/statements/resources/interstitial-lung-disease/IPF-Full-length.pdf | Health Care Professionals | ATS/ERS/JRS/ALAT |
| **Idiopathic pulmonary fibrosis in adults: diagnosis and management** (2017) https://www.nice.org.uk/guidance/cg163 | Health Care Professionals | National Institute for Health and Care Excellence (NICE) |
| **LUNG CANCER** |  |  |
| **Clinical practice guidelines for the treatment of lung cancer** (2018)https://wiki.cancer.org.au/australia/Guidelines:Lung\_cancer | Health Care Professionals | Cancer Council Australia |
| **Guidelines for the diagnosis and treatment of malignant pleural mesothelioma** (2013) http://adri.org.au/wp-content/uploads/2017/11/Guidelines-for-the-diagnosis-and-treatment-of-malignant-pleural-mesothelioma.pdf | Allied health professionals, clinicians, GPs, medical specialists, nurses, radiologists, surgeons | Asbestos Diseases Research Institute (ADRI) |
| **SLEEP DISORDERED BREATHING** |  |  |
| **Guidelines for Sleep Studies in Adults** (2014)https://www.sleep.org.au/documents/item/1112 |  | Australasian Sleep Association |
| **Best practice Guidelines for CPAP therapy** (2009) https://www.sleep.org.au/documents/item/66 | GPs, specialist physicians and business or organisations which intend to provide a CPAP service | Australasian Sleep Association |
| **Definition, discrimination, diagnosis and treatment of central breathing disturbances during sleep** (2017)http://erj.ersjournals.com/content/49/1/1600959 | Health Care Professionals | ERS Task Force |
| **SMOKING CESSATION** |  |  |
| **Supporting smoking cessation: A guide for health professionals** (2014) https://www.racgp.org.au/your-practice/guidelines/smoking-cessation/ | GPs, nurses and other practice staff | RACGP |
| **TUBERCULOSIS** |  |  |
| The BCG vaccine: information and recommendations for use in Australia (2012)  http://www.health.gov.au/internet/main/publishing.nsf/content/cda-cdi3701h.htm |  | The Australian Government Department of Health |
| CDNA National Guidelines For The Public Health Management Of TB (2015) https://www.legislation.gov.au/Details/F2016L00084 | Public Health Units | Communicable Disease Network Australia (CDNA) and the Australian Health Protection Principal Committee (AHPPC) |
| **Management, control and prevention of tuberculosis (2016)** https://www2.health.vic.gov.au/about/publications/policiesandguidelines/tuberculosis-guidelines-2015 | Clinicians and Public Health staff | Department of Health and Human Services, Victoria |
| **AIR QUALITY** |  |  |
| Variation to the National Environment Protection (Ambient Air Quality) Measure https://www.legislation.gov.au/Details/F2016L00084 |  | National Environment Protection Council |

4.5 ENCOURAGE WORKFORCE DEVELOPMENT

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| **TRAINING/COURSES/SYMPOSIUMS** |  |  |
| Annual Respirator Training | Australian/New Zealand Standard AS/NZS1715 requires employers to train and fit-test employees who use respiratory protection on the job. This annual training gives you a chance to explain the importance of respiratory protection and give everyone a refresher course on properly using and caring for their equipment. | 3M Centre for Respiratory Protection |
| Asthma CARE (Collaborative Airway Review and Evaluation) CPD accredited | Asthma CARE is a nurse-led program to help improve the outcome of patients with asthma by focusing on adherence and inhaler technique.  Nurses participating in this program received support and resources to guide them through the 4 main steps: 1. Read: Guided, Self-Learning Module (completion of this module and evaluation form 2. Recall: Using Medical Director and Best Practice to identify and generate patient recall 3. Review: Undertake comprehensive review of adherence and device technique 4. Refer: Patient referral to GP if required The guided self-learning attracted 1.5 CPD hours (ANMF) | GSK is the sponsor. Education module administered by third party education provider. |
| Bachelor of Medical Science (Clinical Physiology) | Undergrad science students: Five eight-point compulsory subjects within the BMedSci (Clin Physiol) in Clinical Measurement, Cardiorespiratory Anatomy & Physiology, Asthma Management, Advanced Respiratory Laboratory Diagnostics, and Advanced Pulmonary Function Testing. Subjects are completed in conjunction with broader medical science studies totalling 92 credit points. | Charles Sturt University |
| Breathe Easy Walk Easy Program | A training program for rural and remote health care providers. This program provides participants with the skills and knowledge to set up and evaluate local pulmonary rehabilitation programs for their patients. The Breathe Easy Walk Easy program has been designed to be delivered to a variety of health professionals, for example: doctors, nurses, Aboriginal health workers, community workers, physiotherapists, occupational therapists, exercise physiologists and all health staff involved in the care of patients with chronic lung disease. | LFA |
| Breathlessness Evening Seminar | Clinical experts cover the key recommendations for recognising, diagnosing and managing patients with breathlessness. | Woolcock Institute of Medical Research |
| COPD Nurse Training and Support Program | Lung Foundation Australia recognises the important role of nurses in the community and across the primary care continuum. To support this role Lung Foundation Australia has developed a program to support nurses in their work with community and patients with lung disease. | LFA |
| COPD Nurse Network | Help empower health professionals in the management of COPD.  Lung Foundation Australia is seeking enthusiastic nurses with respiratory experience to join our national Chronic Obstructive Pulmonary Disease (COPD) Nurse Network. You will play a critical role in delivering training and education to health professionals on COPD management and correct inhaler device techniques.  This is a great opportunity to make a real difference in improving patient care while networking and building further on your credentials. LFA is seeking enthusiastic nurses with respiratory experience to join our national Chronic Obstructive Pulmonary Disease (COPD) Nurse Network. You will play a critical role in delivering training and education to health professionals on COPD management and correct inhaler device techniques.  This is a great opportunity to make a real difference in improving patient care while networking and building further on your credentials. | LFA |
| Difficult-to-treat asthma visiting program | Small group case-based discussion in GPs workplace to improve management of patients with difficult-to-treat asthma. | NPS MedicineWise |
| “Education” for nurses and allied health care professionals | Promote & improve knowledge, skills & networking with peers | The Respiratory Nurses Interest Group NSW Inc |
| Emergency Asthma Management  (10392NAT Course in Emergency Asthma Management) | Nationally Accredited training Course, covering knowledge in What is Asthma, Asthma Triggers, Signs and Symptoms, Medications and Devices and Practical Skills in Asthma First Aid, to provide first aiders with the skills and knowledge to recognise and respond in an asthma emergency. Includes hands-on practice using asthma inhalers and spacers and practical assessment in delivering correct first aid in an asthma emergency. | Asthma Australia |
| eXplore (CPD accredited education) | Interactive case based educational meeting series for GPs and nurses to improve the management of patients with COPD. Learning objectives: - Discuss guideline-recommended step-wise approach in the management of COPD - Summarise the role of different classes of pharmacological therapies in the management of COPD - Identify COPD inhaled medicines by generic and trade names, and which inhaled delivery devices are used with specific medicines - Demonstrate an understanding of the assessment tools used in measuring control of COPD | GSK |
| GASP – Giving Asthma Support to Patients | Practice nurses are provided with intensive training, specialist support and a decision support tool to manage patients with moderate asthma in general practice. They work with their practice manager and GP colleagues to develop work flows to coordinate the optimum management plans for people with asthma, supported by a guidelines-based decision support tool and personal support/supervision from an expert respiratory nurse. | Asthma Australia |
| GP-Patient Dialogue 'Improving asthma care' (CPD accredited) | To improve the outcomes of patients with asthma by enhancing the dialogue between GPs and patients.  Interactive meeting with the following learning objectives: - Uncover the gap between the patient’s perceived level of asthma control - Assess a patient’s readiness to change using the “stages of change” model and communication techniques - Apply communication techniques to change long standing maladaptive perception and behaviours that pose significant health risks. | GSK is the sponsor. Program administered by third party education provider. |
| GP Respiratory Symposium | World renowned Woolcock researchers and clinical experts cover the key recommendations for recognising, diagnosing and managing patients with asthma and COPD. | Woolcock Institute of Medical Research |
| Indigenous Health Worker Spirometry Training Program | To increase the quantity and quality of spirometry performed in Indigenous communities. This culturally appropriate two-day spirometry training program conducted by experienced Respiratory Scientists will assist in the diagnosis and management of lung disease in Indigenous communities. | Indigenous Respiratory Outreach Care Program (IROC) Queensland Health |
| Inhaler Devices In-Clinic Academic Detailing | To educate HCPs about the various inhaler devices and associated techniques. Academic detailing, hands on workshop to be delivered within the practice by trained practising pharmacists on the importance of assessing inhaler technique, hands on workshop with all existing inhalers. | GSK |
| IPF University | IPF University was an initiative of Boehringer Ingleheim Global. It began in 2014 with nurse advisors from 12 countries coming together to devise a strategy and curriculum for educating other healthcare workers in the area of Idiopathic Pulmonary Fibrosis. It is now operational in over 20 countries, including Australia and is taught by nurses trained in the curriculum. The aim is to cover all aspects of care from diagnosis, treatment, comorbidities and quality of life and death. It is currently operational in QLD, NSW, VIC, SA and WA. | Taught by specialist ILD nurses |
| Lungs in Action Full Instructor Training Program | The Lungs in Action Full Instructor Training program has been designed to provide accreditation for personal trainers, fitness instructors, exercise physiologists and physiotherapists to deliver a community-based exercise maintenance program for people with stable chronic lung disease who have completed a Pulmonary Rehabilitation program and people with stable NYHA Class II and Class III Heart Failure who have completed Heart Failure Rehabilitation. | LFA |
| Lungs in Action Online Theory | Lungs in Action Online Theory is a continuing education tool for those who play a role in exercising people with chronic stable lung conditions and/or Heart Failure, or who are a part of a broader multi-disciplinary team that provide these services. It is also a great way for those who choose not to or may not meet the requirements to be a specific Lungs in Action instructor but would still like to expand their knowledge with up to date best practise on exercise safety and limitations with this clientele. The fact that there are now 1 in 7 Australian’s over 40 years of age with COPD (BOLD, 2013) exercise professionals are now faced with an overwhelming number of clients who are diagnosed or show signs of chronic lung conditions. It is important that exercise and health professionals are knowledgeable in this area to ensure safety and optimal outcomes for these clients. | LFA |
| Lungs in Action Practical | The Lungs in Action Practical provides access to the practical component of the Lungs in Action Full Instructor course, for those who have already completed the Lung in Action Online Theory on a separate occasion. | LFA |
| Master of Medical Science | For postgraduate health professionals and scientists to provide upskilling and qualifying in asthma & COPD education, and/or respiratory science.  Four eight-point elective subjects within the MMedSci (with alternate exit points) in Asthma Management, COPD, Advanced Respiratory Laboratory Diagnostics, and Advanced Pulmonary Function Testing. | Charles Sturt University |
| Occupational and Environmental Lung Disease short course | August 2018. Topics: occupational hygiene and the prevention of occupational lung disorders in the mining industry, pneumoconiosis, asbestos-related disorders including mesothelioma, work-related airways diseases (asthma, laryngeal dysfunction COPD), occupational COPD, environmental influences on lung disease and more. | TSANZ |
| Paediatric Respiratory Short Course | October 2018. Topics: the future of respiratory medicine in Australia, paediatric airway, neuromuscular disorders, respiratory research, asthma, chronic cough and bronchiectasis, pneumonia, hi flow in respiratory failure and more. | TSANZ |
| Practitioner Asthma Communication & Education (PACE) Australia Program | Aims to improve paediatric asthma management through effective education and communication with patients and their families.  PACE is an innovative asthma management program, initially developed in the United States and modified for the Australian healthcare setting for general practitioners and pharmacists. The program is based on self-regulation theory and is the most robustly evaluated asthma education program in Australia. | Primary Health Care Education and Research Unit, WSLHD, in partnership with The Woolcock Institute of Medical Research |
| PRECISE (CPD accredited) | Interactive meeting for GPs and nurses to improve the outcomes of patients with asthma and COPD by focussing on adherence, inhaler technique and guideline recommended therapies. | GSK provided the sponsorship. Education program administered by third party education provider |
| Primary Care COPD medicines program | Educational meeting series for GPs to improve the outcome of patients with COPD by focussing on guideline-recommended approach to the pharmacological management options. | LFA developed the clinical content and trained the GSK Clinical Support Specialists (registered Pharmacists) to facilitate in-clinic case study based workshops. |
| Primary Care Inhaler Training Program | In-clinic education to improve the outcome of patients with asthma and COPD by focussing on inhaler technique. | NACA developed the clinical content and trained the GSK Clinical Support Specialists (registered Pharmacists) to facilitate in-clinic workshops. |
| Queensland Health Spirometry Training Program | To train health professionals to perform and interpret spirometry to International and local standards (ATS/ERS, TSANZ). Involves an online course covering the background knowledge and theory behind spirometry practice, followed by a 1 day practical workshop to teach skills, and a workplace portfolio to assess the application of skills and knowledge into practice. The program takes about 3 months to complete. | Queensland Health Spirometry Training Program Review Panel, a subgroup under the governance of the State-wide Respiratory Clinical Network |
| Rare Lung Disease Short Course | A 2-day scientific meeting to educate health care professionals who manage rare lung disease and showcase local and international research | LFA |
| RESpiratory COlloquium (RESCO) | One day symposium for respiratory specialists covering latest evidence in COPD management. | GSK |
| Respiratory update days | Full day seminars to improve the knowledge of healthcare practitioners in the care of patients with respiratory disease | Dept of Respiratory Medicine Westmead Hospital |
| Sleep Technician Training School | Established in 2015, the Woolcock Sleep Technician Training School provides education and training to science and health students interested in sleep medicine. Students are trained in the set up and overnight monitoring of sleep patients as well as CPAP mask fitting, OSA education and CPAP titration method. | Woolcock Institute of Medical Research |
| Smoking cessation and Nicotine Addiction Training Course | Aimed at nurses and other healthcare professionals to improve the implementation and evaluation of programs in smoking cessation. Gain in-depth knowledge and skills in nicotine addiction and smoking cessation to work in primary and allied healthcare as a tobacco treatment and smoking cessation specialist. Topics: Causes, consequences, treatment and research of smoking cessation, nicotine addiction and appropriate evidence based smoking cessation techniques in practical application. | Woolcock Institute of Medical Research |
| State of the Art (SOTA) meeting by Monash Lung and Sleep Institute | State of the art (SOTA) review by experts on various topics in respiratory diseases. An annual one-day symposium convened by Monash Lung and Sleep Institute. The disease area rotates between asthma (2015, 2018), COPD (2016) and sleep (2017). | Monash Lung and Sleep Institute  GSK provided an independent unrestricted educational grant |
| Sydney West Asthma Programs for Schools (SWAPS) | Aimed at teaching staff in primary and high schools to enable appropriate management of students with asthma at school. SWAPS is a partnership program between Western Sydney Local Health District and The Children’s Hospital at Westmead | Primary Health care Education and Research Unit, WSLHD and The Children's Hospital at Westmead. |
| Thunderstorm Asthma Workshop | To support health professionals to be prepared for the thunderstorm asthma season. Learning outcomes are: Describe the phenomena of thunderstorm asthma. Define who is at great risk of thunderstorm asthma Apply current, evidence-based best practice of asthma and allergic rhinitis to professional practice Describe the importance of written asthma action plans and how to use them Implement emergency asthma management and asthma first aid. | National Asthma Council, hosted by Eastern Melbourne PHN |
| **CONFERENCES** |  |  |
| Australasian Cystic Fibrosis Conference | August 2019, Perth  The 13th Australasian Cystic Fibrosis Conference (ACFC) provides a collaborative and educational forum for the CF community and CF professionals to help advance CF research and care. In 2019 our biennial conference brings together health professionals and members of the CF community from around the world to discuss and share ideas on the latest advances in CF research, care and drug development and to exchange ideas about ways to improve the health and quality of life for people with CF. | CFA |
| Australasian Sleep Association Sleep Downunder (ASA 2018) | October 2018, Brisbane | ASA |
| Australasian Tuberculosis Conference | August 2018, Wellington NZ  For two days researchers, clinicians, practitioners and policy makers will gather to debate and discuss tuberculosis management. The conference will provide the opportunity to learn new areas of tuberculosis science, new diagnostic techniques and practices, and develop networks to better improve and coordinate tuberculosis treatment across Australasia. The conference theme is Winds of Change: Tools for TB Elimination. |  |
| Australia and New Zealand Society of Respiratory Science and the Thoracic Society of Australia and New Zealand Annual Meeting | March 2019, Broadbeach Qld | TSANZ |
| Australian Lung Cancer Conference (ALCC) | A 3-day scientific meeting for lung cancer HCPs held second yearly. | LFA |
| Eradicate Cancer Conference | March 2018, Melbourne (inaugural conference) | Sponsored by Victorian Cancer Agency, Victoria State Government. |
| National Asthma Conference | The National Asthma Conference is run every 2 years in a major Australian city. It runs over 2 days, bringing together researchers, practitioners, pharmacists, asthma educators and policy makers from across the country. People have an opportunity to hear about the latest information, research, evidence and practice in asthma diagnosis and management, catch up with colleagues, and learn about Asthma Australia's programs and services. | Asthma Australia |
| National Respiratory Leadership Summit (NRLS) | NRLS is a 1 full day scientific programme (with additional evening symposia) usually with several invited international presenters in addition to a diverse local faculty presenting on the latest scientific evidence and advances in respiratory medicine. NRLS encourages scientific exchange and discussion amongst local and international attendees with a particular focus on local clinical practice relevance. | AstraZeneca Medical |

4.6 WIDEN ACCESS TO OTHER SERVICES, INCLUDING PULMONARY REHABILITATION

This section includes activities aimed at improving access to services, such as MBS rebates, alternate models of deliver (e.g. home-based).

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Domiciliary Home Oxygen Services | The target audience is individuals who meet the eligibility criteria to receive basic oxygen equipment funded by the SA Health Metropolitan Hospital or by the Country SA Local Health Service. Country services assist with the equipment provision, client education, ongoing management, and review. | Community Health Nurses/Respiratory Nurses  CHSALHN |
| Home based pulmonary rehabilitation | Patients attend an initial and final assessment at the centre. One home visit is completed to prescribed exercise and supervise their safety. Patients are provided with a structured home exercise diary and attend weekly motivational interviewing phone calls to progress exercise and provide education about their disease. | HARP services - Alfred Health |
| Home based pulmonary rehabilitation | Clients are provided an initial assessment in a clinic environment and educated about their exercise regime. Following this they undertake their exercise program at home with weekly phone call support by one of our physiotherapists trained in the model and motivational interviewing. At the completion of their 8 week program they are reassessed (6 min walk test). They receive education about managing their health also - simultaneous to the coaching. | The hospital admissions risk program, the Alfred. |
| MBS items | Spirometry, CT scans, other imaging | Australian Government Department of Health |
| MBS Review | The Medicare Benefits Schedule (MBS) Review Taskforce is considering how services can be aligned with contemporary clinical evidence and practice and improve health outcomes for patients | MBS Review Taskforce |
| Mobile Pulmonary Rehabilitation App (m-PR) | To develop a mobile pulmonary rehabilitation platform and evaluate the effectiveness of this platform in conducting pulmonary rehabilitation in the homes of people with COPD. | A/Prof Zoe McKeogh |
| PFOX trial - Pulmonary Fibrosis ambulatory Oxygen Trial | Aimed at people with fibrotic interstitial lung disease to establish the benefits and costs of ambulatory oxygen. Randomised controlled trial with embedded economic analysis comparing ambulatory oxygen to sham ambulatory oxygen in people with fibrotic ILD at 4 Australian and 2 Swedish sites. | Anne Holland PI plus team from La Trobe University |
| REACH trial - Telerehabilitation for chronic lung disease | A randomised controlled equivalence trial to establish whether telerehabilitation provides equivalent benefits to centre-based pulmonary rehabilitation for people with chronic lung disease located in both metropolitan and regional Australia. | Anne Holland, chief investigator, and team from La Trobe University |
| Virtual Clinical Care Home-Telemonitoring Service | Participants are provided with a range of devices to measure relevant clinical parameters and symptoms e.g. glucometer, pulse oximeter, scales, blood pressure monitor and/or thermometer. Results from the home telemonitoring equipment are transferred to the VCC database where they are reviewed once a day by VCC Monitoring Hub nurses. Clinical parameter alerts are established for each participant and incorporated into the VCC database, with low, intermediate and high risk signals being alerted. Clients will be contacted to discuss the most appropriate course of action to address the clinical changes identified. This may include a review by their GP, or an appointment with a respiratory or cardiac nurse. | Country Health SA Local Health Network |

4.7 FACILITATE AFFORDABLE ACCESS TO MEDICATIONS

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| PBS Closing the Gap co-payment | The PBS Closing the Gap co-payment provides eligible Aboriginal and Torres Strait Islander people access to PBS medicines at reduced cost, and in most cases, free of charge. | Australian Government Department of Health |
| PBS prescriptions | Medications for a range of lung conditions are available at the PBS-subsidised rate. | Australian Government Department of Health |

4.8 FACILITATE TIMELY ACCESS TO PROVEN MEDICATIONS FOR RARE DISEASES

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Australian Xolair Registry | A web‐based post‐marketing surveillance registry was established to characterise the use, effectiveness and adverse effects of omalizumab (Xolair) for severe allergic asthma. Registry now closed, data from 192 patients published in 2016. | John Hunter Hospital |
| Biological agent prescription and management of severe asthma | Severe asthma specialist working in private practice and public clinic setting to diagnose, manage all forms of asthma, participate in a local severe asthma MDT and prescribe biological agents | Dr Gregory Katsoulotos (St George Hospital, NSW) |
| Mepolizumab Registry | Collect data (quantitative and qualitative) to monitor improvement/decline, side effects etc of the treatment | John Hunter |
| PBS Closing the Gap co-payment | The PBS Closing the Gap co-payment provides eligible Aboriginal and Torres Strait Islander people access to PBS medicines at reduced cost, and in most cases, free of charge. | Australian Government Department of Health |

4.9 NATIONAL APPROACH TO DOMICILIARY OXYGEN

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Home Oxygen | Patients who meet clinical criteria and have oxygen prescribed by their physician.  Each state/territory runs its own scheme to provide or subsidise the cost of home oxygen. These schemes are quite different in different jurisdictions. There isn’t a national approach that we can identify. | State and Territory government agencies |

4.10 FACILITATE ACCESS TO SUPPORTIVE AND PALLIATIVE CARE

| **Name of activity** | **Target audience/aim** | **Who is running it?** |
| --- | --- | --- |
| Caring@Home | Registered Nurse, General Practitioner, Nurse Practitioner, Community Pharmacist, Allied Health Professional, Carer or Patient caring@home aims to improve the quality of palliative care service delivery across Australia by developing resources that will support people to be cared for and to die at home, if that is their choice. Resources will be available Australia-wide for community service providers, health care professionals and carers to support carers to help manage breakthrough symptoms safely using subcutaneous medicines. | funded by the Australian Government and led by Brisbane South Palliative Care Collaborative |

Priority 5 - Filling the Knowledge Gap: Research funding and research collaborations driving research

5.1 FEEDBACK ON PRACTICE/QUALITY REGISTRIES

There are a number of registries within Australia, however we were unable to locate a comprehensive list for lung disease.

**Australian Bronchiectasis Registry**

Non-cystic fibrosis (non-CF) bronchiectasis is caused by chronic infection of the airways and results in chronic cough, excess sputum production and in some cases chest pain, shortness of breath and coughing up of blood. There is currently no cure for non-CF bronchiectasis and little information is available on the disease’s incidence, diagnosis or mortality rates in Australasia.

The Australian Bronchiectasis Registry is a non-commercial research project that has been initiated by a group of Australian Respiratory Specialist doctors together with Lung Foundation Australia.

The main aims of this registry are to identify and collect health information from patients with non-Cystic Fibrosis (non-CF) Bronchiectasis for doctors to research the causes and to improve treatments. Ultimately, they want to discover a cure or vaccination for this debilitating disease which affects both children and adults.

**Australian Cystic Fibrosis Data Registry**

Cystic Fibrosis Australia funds the management and ongoing development of the Australian Cystic Fibrosis Data Registry (ACFDR).

As treatment breakthroughs and innovation continue to make lives better for people with cystic fibrosis (CF) the ACFDR provides both a clinical perspective and the important statistics that help everyone consistently strive to improve patient care.

The ACFDR is a vital tool for the CF community as it stimulates ground-breaking research, supports clinical teams to improve care, monitors the safety of new medicines and through the ACFDR Annual Report, gives people with CF and their families up-to-date information about the condition.

**Australian Idiopathic Pulmonary Fibrosis Registry**

The Australian IPF Registry has been established by Lung Foundation Australia and is now recruiting.

The registry was established because high resolution computed tomography (CT) scanning has led to earlier diagnosis of IPF, providing physicians with the potential for early intervention of this severe and complex lung condition. As a rare lung disease no single Australian centre has an adequate patient population to facilitate robust research.

Lung Foundation Australia has established the Australian IPF Registry with the generous support of a number of philanthropic families and the Royal Hobart Hospital Research Foundation. Financial support for the Australian IPF Registry is also proudly provided in the form of unrestricted educational grants by various sponsors.

**Severe Asthma Web-based Database (SAWD)**

The Severe Asthma Web-based Database is an electronic data collection platform, utilising the Research Electronic Data Capture (REDCap) database. The authorised study personnel from each individual participating site are responsible for data collection, editing, and also protecting the data being collected at their own site. Quality review/control is the joint responsibility of individual sites and the central personnel [data custodian].

We have been searching for other registries and have been advised there may be another registry for Bronchial Thermoplasty, but we haven’t been able to find information at the time the report was due.

The Australian Commission on Safety and Quality in Health Care published a report entitled “Prioritised list of clinical domains for clinical quality registry development” in this report they have proposed a Prioritised List of Clinical Domains which includes 13 clinical domains however none of these cover lung disease other than Lung Cancer which is included within the High Burden Cancer Clinical Domain.

5.2 INCREASE CAPACITY OF LUNG RESEARCHERS – FACILITATE RESEARCH COLLABORATIVES

There are numerous collaborative structures to support lung researchers and we have included those we could identify below.

The first is a Co-operative Research Centre funded from the Department of Industry and Science.

**Co-operative Research Centre (CRC) for Alertness, Safety and Productivity**

This CRC is a collaboration of industry, government and university sectors in an aim to reduce the burden of impaired alertness on the Australian community. Commencing in 2014, the centre is supported by a government grant of $14.5 million over seven years, and an additional $60 million in academic, industry and non-government organisation funding and in-kind contributions from consortium partners.

The centre has three key programs, the third of which is the Sleep Health Research Program headed by Professor Ron Grunstein. This program recognises that the key features of the two most common sleep disorders, insomnia and obstructive sleep apnoea, vary substantially between individuals. As such, it seeks to develop both new systems for categorising patients, and better tailored and individualised treatment options for sufferers. The other two programs are Alertness Measurement, Prediction and Testing and Safety and Productivity Improvements.

Testing and research within this CRC takes place across five sites within Australia. They include Adelaide Institute of Sleep Health, Flinders University, Monash University, Institute for Breathing and Sleep (Melbourne) and Woolcock Institute of Medical Research (Sydney).

There are also a range of NHMRC funded Centres of Research Excellence in lung disease.

**NeuroSleep - NHMRC Centre for Translational Sleep and Circadian Neurobiology**

NeuroSleep, the Centre for Translational Sleep and Circadian Neurobiology, opened in 2014 with $2.5 million in funding over five years from the [National Health and Medical Research Council Centre of Research Excellence (CRE) scheme](http://www.nhmrc.gov.au/grants-funding/apply-funding/centres-research-excellence-cre).

NeuroSleep’s aim is to improve cognition, workplace safety, and health outcomes in patients with sleep problems such as shift workers, patients with sleep disorders, neurodegenerative and/or mental health problems.

**NHMRC Centre of Research Excellence in Pulmonary Fibrosis**

Pulmonary Fibrosis encompasses a group of lung disorders which share the hallmark of fibrosis or scarring of the lung. The single most prevalent and devastating of these disorders is idiopathic pulmonary fibrosis (IPF), a severe and progressive lung disorder with a median survival of only 2-5 years from diagnosis.

Fund from 2017, the **Centre of Research Excellence in Pulmonary Fibrosis** (CRE-PF) aims to build research capacity in this area. The CRE-PF will enable a nationally coordinated, clinically focused research program to address the urgent need for more effective, personalised approaches to identify and better manage fibrotic lung diseases, as well as to educate the public and train future generations of researchers in pulmonary fibrosis.

**Platform 1: The Australian IPF registry (AIPFR)**

The Australian IPF registry operates on a national level, facilitating collaboration across institutions, States and disciplines to further research into IPF and is the first national IPF registry established in the world. The registry recruits patients from respiratory physicians in every State and Territory in Australia, collecting serial data from participants, physicians and clinical investigations and operates in tandem with a linked biobank that provides researchers with plasma, serum and genetic material on this large and well phenotyped population of IPF patients. With established ties to recognized global centres, the AIPFR provides the opportunity to facilitate both national and international research and collaboration.

**Platform 2: Blood Biobank**

In 2014, a national blood biobank linked to the AIPFR was established. The biorepsository is centrally managed and specimens are stored at the Institute for Respiratory Health in Western Australia. Specimens are collected and stored for IPF registry participants in all states and include DNA, RNA, plasma and serum.

For Stage One recruitment, there are just over 200 patient blood samples.  Stage Two recruitment has commenced and is ongoing.

**Platform 3: PF Lung Tissue Biobank**

Research into the pathogenesis of PF requires access to appropriate tissue specimens. While widespread use of animal models has advanced respiratory research, the gold standard for understanding human physiology and paraphysiology is access to human tissue collected in a standardised fashion from both normal controls and carefully phenotyped PF patients. The Australian PF Lung Tissue Bank will facilitate integration of data from animal models and clinically-phenotyped PF patients to improve the utility of pre-clinical animal models of PF that are on the critical path to new and better medicines.

Lung tissue banks linked to the four Australian lung transplant programs have been established. The CRE-PF will develop a national PF framework, consolidating local initiatives into a single national approach.

This collaborative approach pools resources and will accelerate our understanding of the pathobiology of this fatal disease. Patients with pulmonary fibrosis undergoing lung transplantation provide informed consent for their lung tissue to be stored in the lung tissue bank, allowing the tissue to be accessible for future studies. Each biorepository will collect samples linked to de-identified clinical data that will be available to the pulmonary fibrosis scientific community with appropriate ethical approvals.

Another activity of the CRE-PF is the Pulmonary Fibrosis Australasian Clinical Trials or ‘PACT’ which will conduct randomized, controlled clinical trials to evaluate existing or new medications, combinations of medications, and defined management strategies for patients with PF.

The vision of PACT is to reduce the morbidity and mortality associated with pulmonary fibrosis and improve the quality of life for people living with pulmonary fibrosis, their carers and families in Australia through the facilitation and coordination of high quality clinical research.

**NHMRC Centre for Research Excellence in Respiratory Health of Aboriginal and Torres Strait Islander Children**

The overarching vision of the CRE is to improve the respiratory health of Indigenous children through clinical research.

The specific aims are to:

* generate new knowledge that leads to improved health outcomes
* transfer research outcomes into health policy and/or practice
* develop the health and medical research workforce
* facilitate collaboration
* record research and translation achievements

The CRE team includes clinicians, laboratory scientists, health service delivery experts and community leaders with a combined vision to improve the respiratory health of Indigenous children.

Some of the featured projects include;

* Extension of gene expression signatures in children with and without recurrent protracted bacterial bronchitis (PBB)
* Exploring the PBB microbiome: Do airway bacterial community structures correlate with inflammatory measures?
* ASPP – Asthma and Smoking Prevention Project - a peer-led, asthma education initiative, with an added class smoke free pledge
* Airway bacteriology of children with bronchiectasis.

**NHMRC Centre of Research Excellence in Severe Asthma**

The Centre of Excellence in Severe Asthma brings together researchers from across Australia. Funded by the NHMRC, they are developing innovative approaches to understand why severe asthma occurs, developing [tools](https://www.severeasthma.org.au/tools-resources/toolkits/) and programmes to improve disease management and improving [access to new therapies](https://www.severeasthma.org.au/tools-resources/past-webinars/).

In Australia, 10% of the population have asthma, and a subset have severe asthma. People with severe asthma are at risk of severe attacks of asthma and experience persistent symptoms that are often not controlled with treatment. Severe asthma negatively impacts health and quality of life for individuals and their families and represents a major healthcare cost to our society.

There are two main themes of research.

**THEME 1: Monitoring the Burden of Severe Asthma in Australia**

To better understand the impact of severe asthma the CRE will use disease registers to determine disease prevalence and impact, data linkage analysis to assess patient outcomes and qualitative methods to better understand the experience of patients with severe asthma and improve management approaches.

**THEME 2: Initiatives to Aid Management Of Severe Asthma**

Severe asthma requires a different management approach to mild or moderate asthma. Phenotyping provides personalised information about disease processes in individual patients and allows for rational treatment approaches using new, targeted therapies. The CRE will assess the utility of new diagnostic tests and techniques to better inform patient phenotyping and management.

**NHMRC Centre of Research Excellence in Tuberculosis Control on both sides of our border (Announced by NHMRC 13th August 2018)**

Tuberculosis is the second largest infectious disease killer. Last year Tuberculosis killed nearly 2 million people, closely following HIV/AIDS deaths. Developing better more accessible and affordable diagnostics and therapeutics are urgently needed to reduce TB mortality and morbidity. Limiting the ongoing disease transmission is key to controlling this disease worldwide.

The Tuberculosis Centre of Research Excellence is an interdisciplinary centre of research excellence funded by the National Health and Medical Research Council over 5 years. TB-CRE supports world-class research aimed to improve coordination between and strengthen existing research initiatives on public health interventions, epidemiological and basic science approaches to TB control. The next generation of Tuberculosis researchers will be fostered through the national and international collaborations of the centre.

There are four research themes addressed by this CRE.

**THEME 1: Find and Treat**

**THEME 2: Prevent**

## With the cross-cutting themes of

**THEME 3: Emerging Drug Resistant Tuberculosis**

**THEME 4: Vulnerable Populations**

**NHMRC Centre for Air pollution, energy & health Research**

Established in 2016, CAR is an NHMRC Centre of Research Excellence (CRE) and is an extension of the previous Centre for Air quality & health Research and evaluation (also named CAR).

CAR brings together over 30 researchers from around Australia and internationally in diverse but related disciplines who are at the forefront of their scientific fields. We are based in eight of Australia's most prestigious research institutions.

As a CRE, CAR does not direct research projects but instead supports teams of researchers to pursue collaborative projects and to develop their capacity. CAR does this by providing:

- seed funding and PhD top-up scholarships within one of our research themes  
- symposia, workshops and seminars  
- opportunities for researchers to collaborate  
- training to the next generation of researchers  
- translation of research findings to influence policy and practice in the real world.

The research projects that CAR members work on are based around three themes.

These are the health impacts of:

**Theme 1:** [**Fossil Fuels**](https://www.car-cre.org.au/fossil-fuels)  
 - Improve how we asses and model exposure to air pollution from fossil fuels

- Better understand how health effects change at differing levels of air pollution exposure

- Uncover the mechanisms through which air pollution from fossil fuels affects health

**Theme 2:** [**Energy Transitions**](https://www.car-cre.org.au/energy-transitions)  
- Ways to reduce the health impacts of wood smoke in Australia

- Toxicological effects of biodiesel, wood and biomass burning

- Potential health impacts of new energy sources

**Theme 3:** [**Landscape fires**](https://www.car-cre.org.au/landscape-fires)  
- Improve how we asses and model exposure to landscape fire emissions

- Understand how groups of people are affected by landscape fires

**NHMRC Advanced Health Research and Translation Centres (AHRTC) and Centres for Innovation in Regional Health (CIRH)**

The translation of health and medical research is an integral theme of NHMRC’s strategy for health and medical research. NHMRC has established two initiatives to recognise national leadership in the provision of research-based and evidence-based health care and the training of doctors, nurses and other health professionals: Advanced Health Research and Translation Centres (AHRTCs) and Centres for Innovation in Regional Health (CIRH).

The aim of the AHRTC initiative is to identify and recognise leading centres of collaboration that excel in health and medical research, the translation of evidence into excellent patient care, and demonstrate a strong research and translation focus in the education of health professionals, at an international level. The criteria for recognition as an AHRTC are:

1. Outstanding leadership in research and evidence-based clinical care, including for the most difficult clinical conditions
2. Excellence in innovative biomedical, clinical, public health and health services research
3. Programs and activities to accelerate translation of research findings into health care and ways of bringing health care problems to the researchers
4. Research-infused education and training
5. Health professional leaders who ensure that research knowledge is translated into policies and practices locally, nationally and internationally
6. Strong collaboration amongst the research, translation, patient care and education programs.

In March 2015, NHMRC recognised the first four *NHMRC Advanced Health Research and Translation Centres*:

Melbourne Academic Centre for Health

Monash Partners Academic Health Science Centre

South Australian Academic Health Science and Translation Centre

Sydney Health Partners

In late 2016, NHMRC called for submissions from further interested groups for recognition as an *NHMRC Advanced Health Research and Translation Centre*. As a result, the following groups were recognised as AHRTCs in 2017:

Brisbane Diamantina Health Partners

Sydney Partnership for Health, Education, Research and Enterprise

Western Australian Health Translation Network

The aim of the Centres for Innovation in Regional Health (CIRH) initiative is to encourage leadership in health research and translation of direct relevance and benefit to regional and remote areas of Australia.

In late 2016, NHMRC called for submissions from interested groups for recognition as a CIRH. The following were successfully recognised in 2017:

Central Australia Academic Health Science Centre

NSW Regional Health Partners

A number of State and Territory Governments have established medical research organisations or portfolios within their health departments to coordinate medical research funding, to support infrastructure, for research workforce capacity building and also for members of the public to identify opportunities to participate in local research.

We have been able to identify links for all except Tasmania and Australian Capital Territory;

Office for Health and Medical Research (New South Wales)

NSW Health aims to establish NSW as a global centre of excellence in health and medical research innovation by building on the State’s premier health, research, academic, and medical technology sectors.

Health and Medical Research (Victoria)

The Victorian web page states that Victoria is the premier location for medical research and clinical trials in Australia. This state is recognised as an international leader in health and medical research, and a significant proportion of national government medical research funding is awarded to medical research in Victoria.

Health and medical research (South Australia)

Research is an essential component of SA Health’s mission as it supports innovation, attracts high quality staff, and delivers health, social and economic benefits for South Australia.

Research Development Unit (Western Australia)

The Research Development Unit provides policy and funding support for health and medical research, for both WA Health and the wider WA health and medical research sector.

Health Innovation, Investment and Research Office (Queensland)

The Health Innovation, Investment and Research Office (HIIRO), within the Office of the Director-General, aims to improve the health and wellbeing of Queenslanders through a coordinated and collaborative approach to health innovation, investment and research across Queensland Health.

Health Research (Northern Territory)

The main focus of research in the NT Health has been on evaluation and applied research that explores effective and efficient approaches to promoting health.

5.3 ENSURE PATIENT ACCESS TO CLINICAL TRIALS

Patients who wish to participate in clinical trials would likely perform a Google search for information about clinical trials in their lung disease. To replicate the patient experience we performed a Google search and identified the following leads for patients. The first three are larger scale clinical trial sites that cover multiple lung diseases.

**Australian New Zealand Clinical Trial Registry**

The Australian New Zealand Clinical Trial Registry (ANZCTR) is an online registry of clinical trials being undertaken in Australia, New Zealand and elsewhere.

**Australian Clinical Trials**

This webpage the National Health and Medical Research Council, Department of Industry, Innovation and Science provides opportunities for patients to search for clinical trials or browse by clinical trial categories. Patients also have the opportunity to search for trial sites and the two relevant options provided are Lung Cancer, Lung Disease (Pulmonary Disease) (Respiratory Disease).

**Lung Foundation Australia**

Lung Foundation Australia hosts a “Find a clinical trial” web page and on this page it states “Lung Foundation Australia aim to be the go to resource for people who are living with a lung condition to find a clinical trial.  We are currently exploring how we can keep an up to date list of clinical trials in lung research that are recruiting in Australia – *check back with us soon for regular updates”.* (Accessed 22nd August 2018).

There are a number of additional specific clinical trial registries for Pulmonary Fibrosis, Lung Cancer, Australian Cancer Trials, and Cystic Fibrosis.