We acknowledge Traditional Owners of Country throughout Australia and recognise the continuing connection to lands, waters and communities. We pay our respect to Aboriginal and Torres Strait Islander cultures; and to Elders both past and present.

Development of the National Strategic Action Plan for Lung Conditions and the accompanying document, Summary of the consultation was led by Lung Foundation Australia with funding from the Australian Government Department of Health.

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# **INTRODUCTION**

This document is a supporting document to the National Strategic Action Plan for Lung Conditions (the Action Plan). It provides an overview of the consultation process that was undertaken to formulate the six priority areas identified including objectives and actions for implementation.

Extensive consultation with a broad range of stakeholders was undertaken in the development of the Action Plan. Below is an overview of the activity that occurred as part of the consultation process. A log of the consultation undertaken, and copies of the survey reports are available in the appendices section of this document. The consultation activities included:

* Roundtable of key stakeholders
* Workshop of Senior Managers at Lung Foundation Australia
* Meetings of the Advisory Group (July and August 2018)
* Public Online surveys (July and September 2018)
* Interviews with representatives of state and territory governments (August and September 2018)
* Meetings with Aboriginal and Torres Strait Islander organisations (September 2018)
* Additional contact with content and population group experts throughout the Action Plan development
* Review by Federal Government Departments including:
  + Alcohol and Other Drugs Branch
  + Indigenous Health Division
  + Technology Assessment and Access Division
  + Medical Benefits Division
  + Palliative Care Division

A **roundtable of key stakeholders** was held in October 2017. This half day workshop facilitated by consultants, Communication Link involved representatives of Non-government organisations, consumer groups, patient advocates, research organisations, and clinical experts. Whilst this workshop occurred prior to the funding of the project to develop the Action Plan, it provided valuable input into the early identification of priority areas for action as well as scope and themes to be addressed.

Following the announcement of funding to Lung Fourndation Australia to develop the Action Plan in March 2018, a **workshop** was held with senior management. At this worshop, the scope, themes and potential priority areas for action were drafted in preparation for the first Action Plan **Advisory Group meeting**. The first meeting of the Action Plan Advisory Group was held in early July 2018. This group comprised experts from across the Lung Health sector including consumer representation. Refer to Appendix 1.

Outcomes from the initial Advisory Group meeting informed the **first online survey** which was released for comment in late July 2018. This survey asked participants to:

* Review draft priority areas
* Review draft objectives
* Express opinions on current gaps in service provision, programs and policy.

The results of this survey were published online and are provided in Appendix 2.

Integral to the consultation process were **interviews with representatives from each state and territory health department** about lung conditions. During the course of the interviews information was obtained on activity in each of these jurisdictions including:

* Current work underway to support people with lung conditions
* Areas where there are identified gaps in services, programs and policy
* The highest priority areas identified for action

The jurisdictional representatives consulted were from a variety of different departments in each state and territory with some from Clinical Respiratory Networks and others from Population Health Units or the respiratory department at a health service level. Whilst there was a diversity of representation between states and territories there was consistency in the areas identified for action.

Engagement with the **Aboriginal and Torres Strait Islander** community took the form of a direct approach to service providers including the Indigenous Respiratory Outreach Care Program (IROC) and the Queensland Aboriginal and Islander Health Council (QAIHC). The meeting with IROC was similar in scope to the interviews with the State and Territory health departments. In relation to QAIHC this involved an interactive workshop at the bi-annual Clinical Leaders Forum where the draft priority areas in the Action Plan was presented and feedback was obtained from participants.

In addition to the consultation with jurisdictions and Indigenous organisations, the Action Plan was presented to Lung Foundation Clinical Committees including the General Practice Advisory Group and the Chronic Obstructive Pulmonary Disease (COPD) National Coordinating Committee. Board members of the Thoracic Society of Australia and New Zealand (TSANZ) also participated in the process.

The information collected from all these sources and in consultation with the Advisory Group led to the drafting of the Action Plan. This draft was then released for public consultation in late September via a **second online survey**. The summary of the results of this survey were published online and are provided in Appendix 3.

For both surveys the invitation to participate was distributed via:

* Electronic Direct Mail from Lung Foundation Australia’s communications list of almost 10,000 subscribers
* Direct correspondence Government organisations (including 31 PHNs), peak bodies (43) and research organisations (45) who then shared the invitation through their networks.
* Direct email to Lung Foundation Australia and Thoracic Society of Australia and New Zealand Clinical and Patient committees.

A summary of participation in the online surveys is provided below

|  |  |
| --- | --- |
| **Survey 1: Identifying priorities** | **Survey 2: Draft Action Plan** |
| Total Respondents – 517 | Total Respondents – 361 |
| Involvement from all states and territories – Vic (28%), NSW/ACT (28%), Qld (21.5%), WA (10%), SA (7.5%), Tas (3.5%), NT (1%) National (0.5%), | Involvement from all states and territories - NSW/ACT (36%), Qld (25%), Vic (17%), WA (10%), SA (7%), Tas (2.5%), National (1.5%), NT (1%) |
| 9% representing organisations | 10.5% representing organisations |
| 17% from populations <25,000 | 16% from populations <25,000 |
| 1% identified as Aboriginal and Torres Strait Islander | 1.5% identified as Aboriginal and Torres Strait Islander |
| 153 health professionals (30%) | 118 health professionals (33%) |
| Stakeholders area of interest - People with a lung condition (66%), involved in health service delivery (25%), family members/carers (17%), consumers with an interest in lung health (10%), consumer advocate (8%), Research/academic (8%) | Stakeholders area of interest - People with a lung condition (60%), involved in health service delivery (25%), family members/carers (12.5%), consumer with an interest in lung health (11.5%), Research/academic (10.60%), Consumer advocate (8%) |
| Conditions of interest – COPD (52%), Asthma (41%), Bronchiectasis (37%), Pulmonary fibrosis/ILD (28%), Respiratory infection (25%), Thoracic Cancers (20%), Lung health in Aboriginal and Torres Strait Islander peoples (9%) | Conditions of interest – COPD (59%), Asthma (51%), Bronchiectasis (41%), Pulmonary fibrosis/ILD (33%), Lung Cancer (30%), Respiratory infection (25%), Lung health in Aboriginal and Torres Strait Islander peoples (14%) |

Overall, the consultation process had a reach into every state and territory across Australia. This touched the lives of people affected by lung conditions, their families and the broader community with many sharing their personal stories through the public consultation process. The information shared by this community along with the health professional community, non-government and government organisations has shaped the development of the Action Plan. This clearly represents the community as a whole and outlines a clear path for action to meet areas where there is currently low investment and poor patient outcomes.

The consultation log is provided in Appendix 4.

# **APPENDICES**

## **Appendix 1: Acknowledgements**

Development of the National Strategic Action Plan for Lung Conditions was led by the Lung Foundation Australia with funding from the Australian Government Department of Health.

Development of the Action Plan took place during 2018. Many individuals and organisations contributed time and expertise to the development of the Action Plan, including people with lung conditions and their families, health professionals, key medical and respiratory organisations, the research community and health departments within the Australian Government and State and Territory Governments.

The Lung Foundation sincerely thank the members of the National Strategic Action Plan for Lung Conditions Advisory Group, and all those who participated in the extensive consultation and development phase.

**ADVISORY GROUP**

**Professor Christine Jenkins**, Respiratory Physician and Professor of Medicine, Concord Hospital and University of New South Wales

**Dr. Kerry Hancock**, General Practitioner, Chandlers Hill Surgery, South Australia

**Professor Anne Holland**, Physiotherapist and Professor, Alfred Health Clinical School, LaTrobe University, Victoria

**Professor Guy Marks**, Professor of Respiratory Medicine, South Western Sydney Clinical School, University of New South Wales

**Ms. Deb Kay**, Consumer engagement faculty member of South Australian Health and Medical Research Institute (SAHMRI), South Australia

**Ms. Sara McLaughlin Barrett**, Thoracic Liaison Nurse Consultant, Monash Medical Centre, Victoria

**Professor Adam Jaffe**, Respiratory Paediatrician and Professor of Paediatrics, Sydney Children’s Hospital and University of New South Wales

**Professor Sarath Ranganathan**, Respiratory Physician and Professor, The Royal Children’s Hospital Melbourne and Murdoch Children’s Research Institute, Victoria

**Ms. Tanya Buchanan**, Chief Executive Officer, Thoracic Society of Australia and New Zealand

**Professor Graeme Maguire**, Specialist Physician and Professor, Baker IDI Central Australia and Monash University, Victoria

**Ms. Louise Papps**, Respiratory Nurse Consultant, Black Swan Health, Western Australia

**Dr. Kerry Hall,** Research Fellow and Aboriginal Health Practitioner, Menzies Health Institute, Queensland

**SECRETARIAT**

**Ms. Heather Allan,** CEO, Lung Foundation Australia (until July 2018)

**Mr. Mark Brooke,** CEO, Lung Foundation Australia (from September 2018)

**Ms. Judy Powell**, Advocacy and Policy Manager, Lung Foundation Australia

**Ms. Maree Davidson,** Director, Davidson Consulting (strategy)

**Ms. Rebecca Zosel,** Director, Zosel Consulting (Principal Writer)

**Appendix 2: Summary Report of Online Survey – July to August 2018**

**INTRODUCTION**

As an integral aspect of the consultation process in the development of Australia’s first National Strategic Action Plan for Lung Conditions an online survey was undertaken with stakeholders. Respondents were asked to complete 20 questions with a mix of multiple choice and free text provided via the Survey Monkey platform.

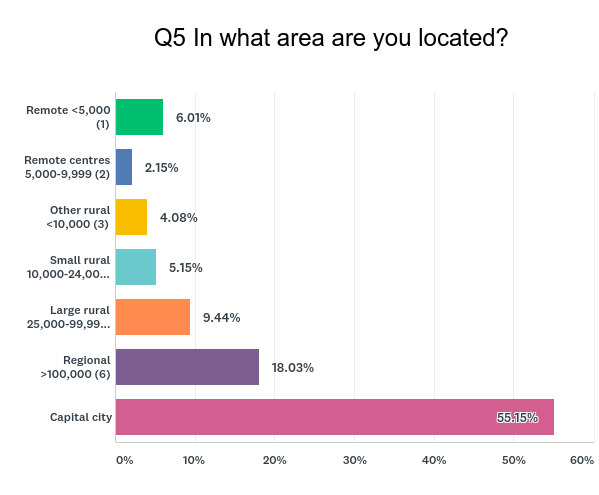
The survey, conducted from late July through to mid-August 2018, sought early input and responses to proposed Priority Areas for action and related objectives, perceptions and experience of positive change or progress in the lung health area and where the gaps are, and suggestions for what needs to be included in the Action Plan.

Development of the Action Plan is being coordinated by Lung Foundation Australia and funded by the Australian Government Department of Health. Its goal is “To improve the lives of all Australians through better lung health”.

**SUMMARY OF SURVEY RESPONSES**

**Who Responded**

More than 500 people completed the survey. Overwhelmingly (91%) respondents participated as individuals, with the remainder (*n*=46 or 9%) representing an organisation viewpoint. These organisations included condition specific groups, professional and peak organisations, academic institutions and government departments. The responses came from all states and territories with the majority coming from Victoria, New South Wales and Queensland. More than half the respondents (55%) came from capital cities, around 18% from large regional centres, 15% from rural centres and 12% from rural and remote areas.

This is a bar graph which highlights that participants were from the following states and territoeis:
ACT = 3%
NSW = 24%
QLD = 22%
SA = 8%
TAS = 3%
VIC = 28%
WA = 10%
NT = 1%
Australia-wide organisations = 1%

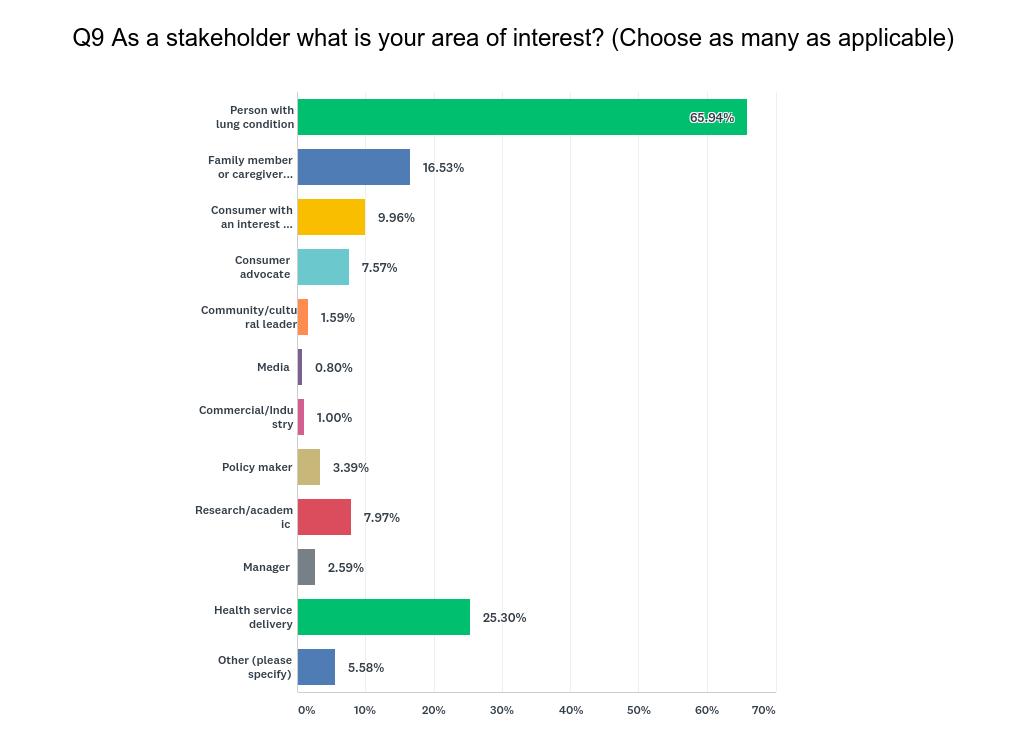
Around three quarters (73%) of those completing the survey were born in Australia. Six respondents (1.3%) identified as an Aboriginal and/or Torres Strait islander person. Of those born overseas, most come from the UK or other English speaking countries.

Of those who responded, 72% registered to join the mailing list to be informed about when the draft Action Plan is available for comment. This indicates the strength of the survey as both a means of consultation and as an engagement tool welcoming a broad spectrum of stakeholders into the ongoing process of developing the action plan.

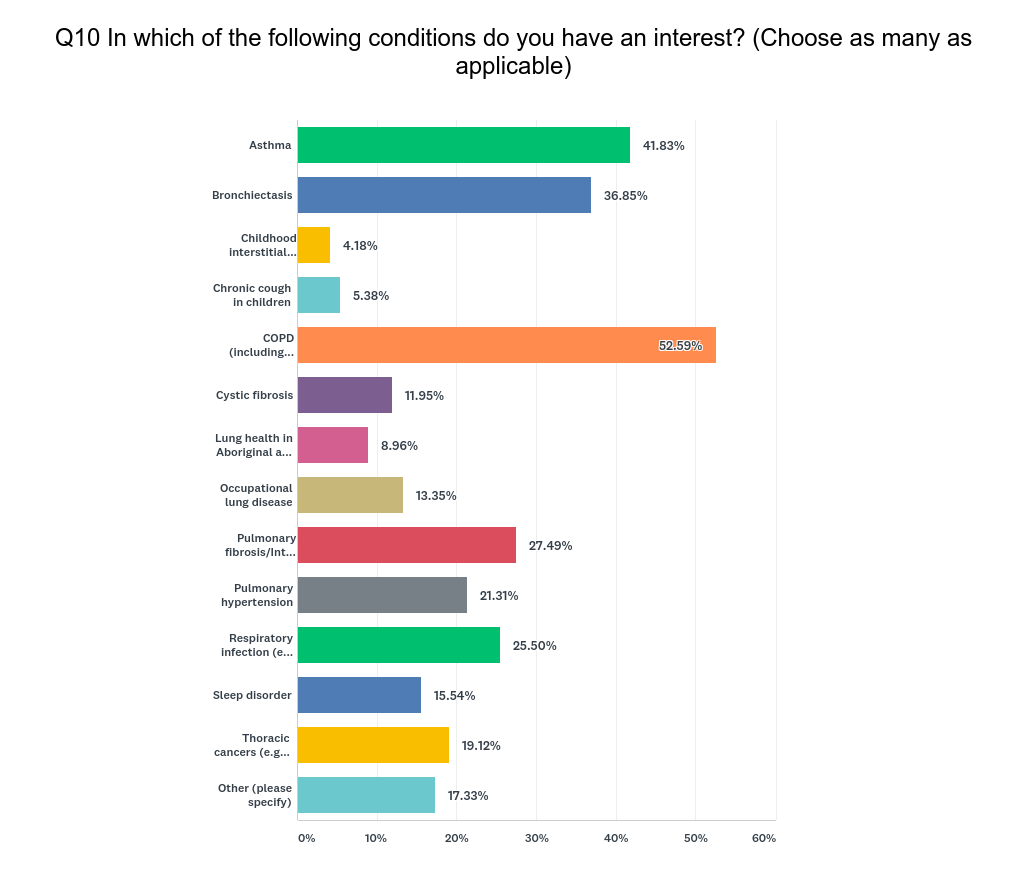
**Stakeholder Area of Interest**

By far the greatest number of responses came from those with a consumer interest – person with lung disease, family member or care giver, consumer advocate and interested consumer. This was followed by health service delivery and research/academia. Respondents were able to choose multiple response options so the total exceeds 100%.

Health professionals comprise just over a quarter of the responses. Almost one third of these were nurses, 22% medical doctors or specialists and 12% physiotherapists. Other health professionals involved in providing care for people with lung conditions made up the balance of responses.



The conditions in which respondents have an interest is varied with many respondents choosing more than one area. COPD (including Alpha1 antitrypsin deficiency), asthma and bronchiectasis were the most selected areas followed by pulmonary fibrosis/interstitial lung disease, respiratory infection, pulmonary hypertension and thoracic cancers.



**Scope of the Action Plan**

The Action Plan has a limit of five areas for action which were provided in the survey. Respondents were asked to suggest any additional priority area that may be required, and if so, to nominate which existing area be replaced.

*Proposed Priority Areas*

1. *Breathing well*

*Prevent lung conditions and enhance lung health*

1. *Supportive communities*

*Increase community understanding of lung health*

1. *Health care partnerships*

*Enable people and health professionals to be partners in management of lung conditions*

1. *Best care for all*

*Ensure equity of access to evidence-based management of lung conditions*

1. *Improved knowledge*

*Increase knowledge about prevention, diagnosis and management of lung conditions*

There is general support for the existing priorities although it is apparent that some areas for action need to be expressed more explicitly. Following are some aspects that respondents suggest be highlighted in the current priority areas and their supporting objectives:

* *Supportive communities* - Stigma associated with lung conditions needs to be highlighted.
* *Health care partnerships* – Rather than building health care capacity, respondents suggested that this objective should focus on the need for workforce development including GP education and improvements to care coordination systems and processes.
* *Best care for all* – Inclusion of diagnosis was suggested in this priority to ensure that both diagnosis and management are covered.
* *Improved knowledge* – Need to replace this term with the word ‘Research’ so that this priority is better understood.

Many respondents offered suggestions for a range of other specific actions within each priority area. These specific actions focused on access to treatments, supporting quality of life, environmental triggers and research into rare lung diseases.

**Progress in Lung Health**

Many examples of successes or recent progress at a personal and systems level were nominated by respondents. These include but are not limited to:-

* Improvements in and greater variety of available medications.
* Sustained decrease in smoking rates and controls regarding environmental tobacco smoke.
* Reduction in asthma deaths since the 1980s and improved asthma management.
* Access to quality pulmonary rehabilitation.
* Improved workplace hazard protection.
* Better diagnosis and support through multidisciplinary teams.

There are indications that although progress is being made in some lung conditions and approaches to prevention, treatment and management this is inconsistent and not widespread.

It is apparent from the responses to this and the following question that what is for some an area of progress is for others an area requiring attention e.g. access to pulmonary rehabilitation. Some respondents used this question as an opportunity to state that for them there has been no progress or improvement in the recognition of their condition, treatment, available services or research.

**Areas Requiring a Response or Improvement**

The majority of suggestions about gaps and necessary improvements relate to the *‘Best care for all’* priority although there are numerous and specific contributions across the other proposed priority areas.

These include:-

|  |  |  |
| --- | --- | --- |
| **Priority** | **Actions** | **Detail** |
| *PA1 – Breathing Well: Prevent lung conditions and enhance lung health* | Improve air quality | * Indoor (e.g. fragrances, fumes) * Outdoor (e.g. emissions, dust, smoke, fumes) |
| Occupational risks | * Occupational groups (welders, stone cutters) * Reduce exposure to physical, chemical and biological hazards |
| Tobacco control | * Smoking in specific population groups (e.g. Aboriginal and Torres Strait Islander People, young women, people with mental health conditions, children, and teenagers) including passive smoking * Legislation to eliminate tobacco. Ban use of tobacco in public places |
| *PA2 – Supportive Communities: Increase community understanding of lung health* | Reduce stigma | * Link between smoking and lung conditions |
| Awareness of symptoms for people at risk of lung conditions | * Lung cancer |
| Need for support groups to reduce isolation | * Provide psychosocial support |
| *PA3 – Health Care Partnerships: Enable people and health professionals to be partners in management of lung conditions* | Access to disability support | * NDIS, Centrelink |
| Self-management support for patients and care givers | * Education through a variety of media including telehealth and direct from independent organisations and/or health professionals. Topics cover managing breathlessness, exacerbations, exercise, smoking, nutrition, weight management, medicine adherence including inhaler device technique, action plans * Support groups and forums * Peer to peer support * Health literacy incorporating understanding of conditions, navigation of the health care system and ability to communicate effectively with health care and other services |
| Education for health professionals, especially GPs on identification, diagnosis and management of lung conditions | * Post-graduate * Competency standards and credentialing * Education around communication and counselling skills given the number of respondents who shared personal experiences of stigma and the psychosocial burden of lung conditions. |
| Use of technologies by health professionals to facilitate and support implementation of evidence-based management. | * This could include action plans at point of care and automatic referral mechanisms |
| Funding mechanisms to support evidence-based practice | * MBS billable items for management of lung conditions (e.g. action plans, pulmonary rehabilitation) * Increase rebate for diagnostic testing (e.g. spirometry) |
| *PA4: Best Care For All: Ensure equity of access to evidence-based management of lung conditions* | Diagnosis | * Early diagnosis (e.g. COPD, pulmonary hypertension, lung cancer, alpha-1 antitrypsin deficiency, sarcoidosis) * Improved diagnostic testing |
| Lack of access to evidence-based management | * Programs/services (e.g. Pulmonary rehabilitation, Lungs in Action, smoking cessation) * Medicines (e.g. cost) * For people living in rural and remote areas (e.g. specialists services, GPs, allied health services, pulmonary rehabilitation) * For culturally and linguistically diverse people * Oxygen * Co-morbidities (e.g. mental health, GORD, heart failure) |
| Care coordination/communication | * Effective referral process to engage the entire MDT including specialists * Access to patient navigators/care coordinators/specialist nurses trained in lung conditions (e.g. lung cancer nurses, respiratory nurses) * Partnerships between primary and tertiary care including palliation |
| Models of care suggested | * Specialist clinics * Breathlessness intervention service * Outreach services/Telehealth |
| *PA5: Improved Knowledge: Increased knowledge about prevention, diagnosis and management of lung conditions* | Research for new medicines and effective treatment options |  |
| Research into lung conditions (e.g. lung cancer, respiratory infections, alpha-1 antitrypsin deficiency, ILD, PF, LAM, bronchiectasis, scleroderma, rare lung disease, mould related lung disease) | Access to:   * Studies/clinical trials * Better data including Australian data (e.g. prevalence, high risk environments, benchmarking) |
| Establish national registers | * Alpha-1 antitrypsin deficiency |
| Equity of funding for research |  |
| Search for a cure |  |
| Research in: | * Effective management post lung transplant * Occupational exposures in emerging industries and effective protection * Facilitators and barriers to patient adherence * Implementation and translation of best practice management * Air quality (e.g. multiple chemical sensitivity) * Development of valid reference values for Aboriginal and Torres Strait Islander People for spirometry testing * Biomedical areas (e.g. stem cell lung growth) |

**Conclusion**

This survey has provided an invaluable insight for those charged with the task of developing the National Strategic Action Plan for Lung Conditions. Combined with the published literature, available data, a national stock take of programs and services and extensive consultation this lived experience and the thoughtful suggestions provided in the survey will contribute significantly to the Action Plan. The resulting outcome will be improved Lung Health for all Australians.

**Appendix 3: Summary Report of Online Survey – September to October 2018**

**INTRODUCTION**

As an integral aspect of the consultation process in the development of Australia’s first National Strategic Action Plan for Lung Conditions a second online survey was undertaken with stakeholders. Respondents were asked to complete 20 questions with a mix of multiple choice and free text provided via the Survey Monkey platform.

The survey, conducted from late September through to early October 2018, sought feedback from the public on the draft of the Action Plan. This draft was developed following:

* Roundtable discussion October 2017
* Advice from an expert Advisory Group
* Literature review
* Public Survey conducted from late July through to mid-August 2018
* Meetings with Aboriginal and Torres Strait Islander Groups
* Meetings with State and Territory health department representatives
* National Stocktake of lung health programs and services

Development of the Action Plan is being coordinated by Lung Foundation Australia and funded by the Australian Government Department of Health. Its goal is “To improve the lives of all Australians through better lung health”.

**SUMMARY OF SURVEY RESPONSES**

**Who Responded**

More than 360 people completed the survey. Overwhelmingly (89.5%) respondents participated as individuals, with the remainder (*n*=38 or 10.5%) representing an organisation viewpoint. These organisations included condition specific groups, professional and peak organisations, academic institutions, service providers, industry/commercial organisations and government departments. The responses came from all states and territories with the majority coming from New South Wales, Queensland and Victoria. More than half the respondents (55%) came from capital cities, around 17.5% from large regional centres, 19% from rural centres and 8.5% from rural and remote areas.

Three quarters (75%) of those completing the survey were born in Australia. Five respondents (1.5%) identified as an Aboriginal and/or Torres Strait islander person. Of those born overseas, most came from the UK or other English speaking countries.

**Stakeholder Area of Interest**

By far the greatest number of responses came from those with a consumer interest – person with lung disease, family member or care giver, consumer advocate and interested consumer. This was followed by health service delivery and research/academia. Respondents were able to choose multiple response options so the total exceeds 100%.

Health professionals comprised almost one third of the responses. Nurses made up 34% of the respondents followed by 18% medical doctors or specialists and 8.5% physiotherapists. Other health professionals involved in providing care for people with lung conditions made up the balance of responses.

The conditions in which respondents have an interest varied with many respondents choosing more than one area. COPD (including Alpha1 antitrypsin deficiency), asthma and bronchiectasis were the most selected areas followed by pulmonary fibrosis/interstitial lung disease, lung cancer, respiratory infection, and pulmonary hypertension.

**Structure of the Action Plan**

Respondents were provided with the copy of the Draft of the National Strategic Action Plan for Lung Conditions and asked to provide feedback on the structure and content.

Eighty percent (80%) of respondents strongly agreed or agreed that the structure of the **overall plan** is appropriate and easy to follow. Comments in relation to the structure of the plan included:

* The structure of the Action Plan was comprehensive, logical and easy to follow
* Identification of appropriate priorities with rational drivers
* Formatting suggestions
* Long and complex
* Need executive summary
* Lack of clarity on what success looks like.
* The intended outcomes of each action should be placed first.

Respondents were asked about the sections in the Action Plan related to the Introduction and Lung Conditions in Australia. Almost 90% of respondents agreed or strongly agreed that the introduction and Lung Conditions in Australia sections of the Action Plan provided a clear strong case, context and background for why action is required for people impacted by lung conditions.

Comments in relation to the Introduction and Lung Conditions in Australia section included:

* The need to include asthma as a priority condition
* Lack of emphasis on lung cancer detection and screening
* Balancing the conversation to encompass acute and chronic lung conditions
* A compelling case for improved action on lung disease is presented
* Economic impact section could be introduced earlier and be quantified
* Suggestion to include a pictorial on the link between this action plan and other plans and frameworks
* Key stakeholders could be named
* Highlight the priority populations

**Priority Areas**

Respondents were asked about each priority area and if they agreed that the information presented in each section adequately addressed the key areas for action.

For priority area 1 which relates to Prevention and Risk Reduction, almost 85% of respondents agreed or strongly agreed that the information in this section adequately addressed the key areas for action.

Comments in relation to Priority Area 1 included:

* Efforts around tobacco should not further stigmatise those with lung cancer
* Inclusion of asthma in occupational lung disease and air quality work
* Make occupational lung disease a notifiable condition
* Engage relevant agencies in relation to indoor and outdoor air pollution
* Good lung health management during pregnancy
* Legislation on workplace exposures, standards for investigation and diagnosis and improved access to compensation is needed.
* Effects of housing, infection and smoking education should be included for priority populations
* Links with Healthpathway projects
* Add tobacco smoke as a key risk factor including early childhood exposure and e-cigarettes
* Role of risk reduction in treatment

For priority area 2 which relates to Awareness and Stigma, over 81% of respondents agreed or strongly agreed that the information in this section adequately addressed the key areas for action.

Comments in relation to Priority Area 2 included:

* Awareness campaign needs to be supported with long term strategies to achieve true behaviour change.
* Blend the awareness and stigma priority area with other priorities in the Action Plan such as education for health professionals and systems at the patient/practitioner interface.
* A coalition of organisations is required to partner in delivery of awareness and stigma campaigns
* Need to encompass a broad range of lung conditions in any campaign and include vulnerable populations such as culturally and linguistically diverse communities.

For priority area 3 which relates to Diagnosis, Management and Care, over 77% of respondents agreed or strongly agreed that the information in this section adequately addressed the key areas for action.

Comments in relation to Priority Area 3 included:

* The section is logical and easy to follow with sound actions and strategies
* Late diagnosis, under-diagnosis and misdiagnosis important issues to address for all lung conditions
* Need to include more lung conditions in clinical practice guidelines including brief translations to support practice.
* Models of care such as optimal care pathways for lung cancer.
* Focus on education for health professionals on the safe and effective use of medicines and other evidence based management strategies for people with lung conditions is vital
* Need to completely overhaul spirometry training and funding nationally
* Greater need for respiratory nurses and other respiratory staff (scientists, specialists) at the local level
* Potential to extend currently funded training to include more lung conditions and link with existing training frameworks
* Proposed actions are good but lack specific detail such as GP MBS items and potential organisations to assist in implementation of actions.
* Extend to include clinical trials
* Too many areas of action with no apparent clarity on relative importance of any one thing over another.
* Priority areas and enablers need to be clearly linked to and inform each other.

For priority area 4 which relates to Partners in Health, almost 81% of respondents agreed or strongly agreed that the information in this section adequately addressed the key areas for action.

Comments in relation to Priority Area 4 included:

* The multi-disciplinary team can be involved in self-management including pharmacy
* Assumptions shouldn’t be made by health professionals and it is important to have conversations about difficult issues such as end-of-life care and completing advance care directives. They need to be part of routine care and introduced as early as possible.
* Existing self-management services should be acknowledged and supported.
* Many tools are available and could be adapted for the Australian context.
* Technologies used in other disease areas could be used for people with lung conditions.
* Work should be delivered in a way that is integrated and programs/services open to being flexible to be linked together and wrapped around the needs of people with lung conditions.
* Health literacy of patients/clients is important where self-management and active participation in care is a priority.
* An APP to support coaching of patients and link with health professionals for review.
* Emphasis on Aboriginal and Torres Strait Islander people and culturally and linguistically diverse communities required.

Pulmonary rehabilitation training has provided me the knowledge to improve and manage my own condition (COPD) but most importantly to almost eliminate my panic attacks.

For priority area 5 which relates to Equitable Access, over 77% of respondents agreed or strongly agreed that the information in this section adequately addressed the key areas for action.

Comments in relation to Priority Area 5 included:

* Pulmonary rehabilitation should be available for all people with chronic lung conditions
* Health literacy has an impact on the ability of patients and carers to access health services
* Funding model (MBS item no.) needed to support health professionals to deliver education for patients
* Funding for specialist nurses to cover all lung conditions may be useful
* Flexible approach to workforce in rural and remote – generalist rather than specialist
* Need equitable access to in home support
* The savings of pulmonary rehabilitation to the healthcare system if 90% of patients completed instead of 10% would be enormous.
* Staffing for respiratory positions for regional facilities is around 20% of the cardiac resources! WHY??

For priority area 6 which relates to Research and Monitoring, almost 79% of respondents agreed or strongly agreed that the information in this section adequately addressed the key areas for action.

Comments in relation to Priority Area 6 included:

* What about the very great need for an Australian Lung Cancer Registry? Funding for Australian CF data registry?
* Research required into Australian conditions – almost all research is from countries outside of Australia.
* Details on amount of funding and how it will be administered are limited in the draft
* Differentiate between the basic research (needed in some areas) and implementation/translation research.
* Better alignment of research investment to disease burden also needs to be considered
* There could be a stronger focus on biological research into lung disease, not only epidemiology/quality of health care.
* The lack of career stability and ongoing funding for researchers leads to very risk averse research and can lead to promising projects being abandoned.

**Achieving progress**

Almost 78% of respondents strongly agreed or agreed that the structure of the **achieving progress section** of the Action Plan provided clear information on how the Action Plan will be monitored and measured. Comments in relation to this section included:

* There is no timeframe given for the Action Plan.
* The details provided on how the Action Plan will be monitored and measured are limited. Who will deliver this activity was also missing.
* Feedback mechanisms should be included to inform future strategies.
* The outcomes are quire broad and no measurable goals or targets have been articulated.
* While the process is clear, there is too much being committed, and further prioritisation is needed.
* Establishment of benchmarks required to measure each criteria and improvements over time.

**Conclusion**

This survey has provided valuable feedback on the draft Action Plan. Generally, there is consensus that the plan is well structured, easy to follow and addresses the priority areas for action in relation to lung conditions. Questions were raised on a variety of different aspects of the Action Plan including who will be involved in implementation, how this will be delivered and a need for more detail on measuring outcomes. Other feedback provided by respondents focused on issues in relation to singular lung conditions, priority populations and areas of management such as palliative care. This information will be utilised to draft the final version for consideration by the Commonwealth Department of Health.

**Appendix 4: Consultation Log**

|  |  |  |  |  |
| --- | --- | --- | --- | --- |
| Date | Organisation | Mode | Focus | Comments |
| 12-Dec-18 | Department of Health: - Alcohol and Other Drugs Branch - Indigenous Health Division - Technology Assessment and Access Division - Medical Benefits Division - Palliative Care Division | Email | Review | Received feedback to enhance the Action Plan |
| 15-Oct-18 | AMSANT, Alice Springs | Email | Completed survey | Response provided. |
| 9-Oct-18 | Western Victoria PHN | Email | Consultation | Offered to assist with consultation |
| 8-Oct-18 | Tasmanian Aboriginal Centre | email | Completed survey | Survey submitted in word document via email. |
| 3-Oct-18 | Captial Health Network (ACTs PHN) | Email | E-newsletter |  |
| 3-Oct-18 | Pharmacy Guild of Australia | Email | Survey |  |
| 28-Sep-18 | Brisbane South PHN | email | Launch of Draft Action Plan for public consultation | Newsletter article. |
| 28-Sep-18 | Australian Institute of Occupational Hygienists | Phone and email | Launch of Draft Action Plan for public consultation | Specific request for Indoor Air Quality SEG at AIOH to comment on the Action Plan. |
| 25-Sep-18 | RACGP Respiratory Specific Interest Group | Email | Launch of Draft Action Plan for public consultation | Links to access the survey sent to all members. |
| 25-Sep-18 | Cancer Institute NSW | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Safercare Victoria | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Tasmanian Government | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | SA Government | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Qld Government | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | ACT Government | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | NT Government | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Pulmonary Hypertension Network Australia | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. The survey has been shared with the network. |
| 25-Sep-18 | West Moreton Darling Downs PHN | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Asthma Australia (National Office) | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | National Asthma Council | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Acknowledgement of receipt of email. |
| 25-Sep-18 | Asthma Australia (SA Office) | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-15 | Australasian Sleep Association | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-15 | Murray PHN | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Completed the survey. |
| 25-Sep-18 | Council on the Ageing (COTA) | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Australian Association of Consultant Pharmacists (AACP) | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Agreed to share in e-news. |
| 25-Sep-18 | Rural Doctors Workforce Agency | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Acknowledgement of receipt of email. |
| 25-Sep-18 | Rural Health West | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Check UP | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Will share in next Reaching Out newsletter. |
| 25-Sep-18 | The Society of Hospital Pharmacists of Australia | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | The Pharmacy Guild of Australia | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Thoracic Society of Australia and New Zealand (TSANZ) | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Will share with networks. |
| 25-Sep-18 | Cystic Fibrosis | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Tasmanian PHN | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Australian College of Rural and Remote Medicine (ACRRM) | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Exercise and Sports Science Australia (ESSA) | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Acknowledgement of receipt of email. |
| 25-Sep-18 | Immunisation Coalition | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Woolcock Institute | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Australian Primary Care Nurse Association (APNA) | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Will put it in their newsletter. |
| 25-Sep-18 | Coordinaire: South Eastern NSW PHN | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Western NSW PHN | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Captial Health Network (ACTs PHN) | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Passed on to the communications Manager and will discuss with fellow clinicians and patients. |
| 25-Sep-18 | Hunter New England and Central Coast PHN | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Western Victoria PHN | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Adelaide PHN | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | South Eastern Melbourne PHN | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Brisbane South PHN | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. This is scheduled to go out with weekly eBlast. |
| 25-Sep-18 | Cancer Council Australia | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Received an acknowledgement that they got the EDM too. |
| 25-Sep-18 | North Coast PHN | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Pharmaceutical Society of Australia (National Office) | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | NSW Rural Doctors Network | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | NPS MedicineWise | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Indicated that they will complete the survey. |
| 25-Sep-18 | Consumers Health Forum | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Agency for Clinical Innovation, NSW | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Agreed share with networks. Sent on to Cancer Institute NSW |
| 25-Sep-18 | FECCA | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. Agreed to share with networks. |
| 25-Sep-18 | IROC | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Qld Respiratory Network | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. The survey has been shared with the network. |
| 25-Sep-18 | WA Respiratory Network | Email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. The survey has been shared with the network. |
| 25-Sep-18 | Menzies Health Institute Qld | Email | Launch of Draft Action Plan for public consultation | Shared online survey with all Indigenous contacts. |
| 25-Sep-18 | QAIHC | email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | Palliative Care Australia | email | Launch of Draft Action Plan for public consultation | Query on th inclusion of supportive and palliative care in the Action Plan. |
| 25-Sep-18 | NACCHO | email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. This has been shared with CEO's Forum Policy Subcommittee, Policy Subcommittee CC List |
| 25-Sep-18 | NT PHN | email | Launch of Draft Action Plan for public consultation | Links to access the survey. Request to participate and share with networks. |
| 25-Sep-18 | NT PHN | email | Face to face meeting | Feedback on an EDM on the meeting set up to discuss the outcomes of the public consultation on the Draft Action Plan. |
| 25-Sep-18 | LFA communications list | email | Launch of Draft Action Plan for public consultation | Link to download draft and complete survey. |
| 19-Sep-18 | NACCHO | phone meeting and email | Aboriginal and Torres Strait Islander Consultation | Engagement in online survey. Sharing with network. Future collaborations if funding is provided. |
| 18-Sep-18 | QAIHC | Presentation and worskhop | Aboriginal and Torres Strait Islander Consultation | Lead Clinicians Group Forum - workshop to engage around the proposed priorities, objectives and actions for the NSAPLC. |
| 14-Sep-18 | SA Health | phone meeting and email | Jurisdiction consultation | Discussed background and progress of NSAPLC. Put forward questions to consider. Provided a summary of the status of lung conditions in SA. |
| 11-Sep-18 | SA Health/TSANZ Board | phone meeting and email | Jurisdiction consultation and clinical perspective | Discussed background and progress of NSAPLC. Put forward questions to consider. Provided a summary of the status of lung conditions in SA. |
| 11-Sep-18 | QAIHC | face to face meeting | Aboriginal and Torres Strait Islander Consultation | Potential for meeting with lead clinicians group. |
| 6-Sep-18 | Indigenous Respiratory Outreach Care Program (IROC) | face to face meeting | Aboriginal and Torres Strait Islander Consultation | Discussed progress and timelines of NSAPLC. Put forward questions to consider. Provided a summary of the status of Indigenous respiratory outreach services and advice on the best approach. |
| 3-Sep-18 |  | email | PDF of online survey | Copy of online survey requested. |
| 3-Sep-18 | WA Respiratory Network | phone meeting and email | Jurisdiction consultation | Discussed background and progress of NSAPLC. Put forward questions to consider. Provided a summary of the status of lung conditions in WA. |
| 3-Sep-18 | Qld Health Respiratory Network | phone meeting | Jurisdiction consultation | Provision of update on the progress of the development of the NSAPLC. Request to present at Forum - October 12th |
| 30-Aug-18 | Tasmanian Health Dept. Population Health | phone meeting and email | Jurisdiction consultation | Discussed background and progress of NSAPLC. Put forward questions to consider. Provided a summary of the status of lung conditions in Tasmania. |
| 30-Aug-18 | SA Health | email | Meeting request | Follow up of email from Aug 9. Shelley away for 2 weeks and advised that Penny Thyer would be in contact to arrange a meeting. |
| 30-Aug-18 |  | email | PDF of online survey | Copy of online survey requested. |
| 29-Aug-18 | National Asthma Council of Australia (NACA) | email | NSAPLC | E-newsletter |
| 29-Aug-18 | NACCHO | email | Meeting request |  |
| 27-Aug-18 | QAIHC | Phone and email | Meeting arranged. | Meeting arranged to discuss NSAPLC with Wayne and Angela Young (Policy). Set for September 11th. |
| 27-Aug-18 | Tasmanian PHN | email with letter | Contact person | Nomination of contact person. Info provided on identification of need and current commissioning of services in relation to lung conditions. Potentially add to NSAP mailing list. |
| 27-Aug-18 | Safercare Victoria | phone meeting and email | Jurisdiction consultation | Discussed background and progress of NSAPLC. Put forward questions to consider. Provided a summary of the status of lung conditions in Victoria and advice on the best approach. |
| 23-Aug-18 | ACT Health | phone meeting and email | Jurisdiction consultation | Discussed background and progress of NSAPLC. Put forward questions to consider. Provided personal perspective as a specialist. Emailed through link to European position statement on lung cancer screening. |
| 23-Aug-18 | Aboriginal Health and Medical Research Council of NSW | email | Request for a meeting | Potential for meeting to discuss NSAPLC |
| 23-Aug-18 |  | email | PDF of online survey | Copy of online survey requested. |
| 22-Aug-18 | NSW Health ACI | phone meeting and email | Jurisdiction consultation | Discussed background and progress of NSAPLC. Put forward questions to consider. Agreed to ask share with Respiratory Network Executive for feedback. Will provide contacts for cancer. When approved by minister will share economic appraisal and recommended inteventions based on current work around identification of barriers and enablers. |
| 21-Aug-18 | SA Health | Phone and email | Stocktake | Timeline for submission. I resent the survey links for contribution from SA |
| 20-Aug-18 | Queensland Health | email | Jurisdiction consultation | Summary of meeting. |
| 17-Aug-18 |  | email | PDF of online survey | Copy of online survey requested. |
| 16-Aug-18 | Queensland Health | Face-to-face | Jurisdiction consultation | Discussed background and progress of NSAPLC. Put forward questions to consider. Agreed to ask system planning branch to look at questions. |
| 14-Aug-18 | NPS MedicineWise | email | Online survey/stocktake | Participated in stocktake but not online survey. Not enough clinical focus in online survey. |
| 14-Aug-18 | Gold Coast PHN | email | Online survey | E-newsletter |
| 14-Aug-18 | Qld Health Respiratory Network | Face-to-face and email | Face to face meeting | Discussed background and progress of NSAPLC. Put forward questions for the network to considered. Invitation extended to JP to attend next Steering Committee. |
| 14-Aug-18 | Minister for Health; Mental Health, WA Health Dept. | letter | contact people | Advice on contact people for WA |
| 13-Aug-18 | Consumer | email | Online survey | Suggest that lung cancer and mesothelioma be seperated from thoracic cancers in the aciton plan. |
| 13-Aug-18 | Brisbane ME/CFS Support | email | Provision of information | Data on CFS. Climate change as an issue. |
| 10-Aug-18 | Qld Health Respiratory Network | email | Face to face meeting | Calendar invite confirmed |
| 10-Aug-18 | Safercare Victoria | email | Meeting request | Arranging meeting times. |
| 10-Aug-18 | NSW Health ACI | email | Meeting request | Request for a meeting to discuss priorities. |
| 10-Aug-18 | NSW Health | Email and letter | Contact person | Confirmation of contact person for LFA to liaise with in relation to NSAPLC |
| 10-Aug-18 | Cancer Council Australia | Phone and email | Phone meeting | Identification of priority areas for action in lung cancer and tobacco control. Documents and links provided. |
| 10-Aug-18 | Brisbane ME/CFS Support | Email and phone | Online survey | supply of additional information on prevalence. |
| 10-Aug-18 |  | email | PDF of online survey | Copy of online survey requested. |
| 9-Aug-18 | Safercare Victoria | email | Face to face meeting | Introduction to contact to arrange meeting. |
| 9-Aug-18 | NSW Stone Industry Taskforce | email | Online survey | Invitiation to paticipate in the online survey. |
| 9-Aug-18 | NPS MedicineWise | Email and letter | Stocktake | Engagement in stocktake and online survey. |
| 9-Aug-18 | SA Health | email | Meeting request | Request to share online survey and for a meeting to discuss priorities. |
| 9-Aug-18 | QAIHC | phone | Meeting request | Follow up call and then sent email. |
| 8-Aug-18 | NSW Rural Doctors Network | email | Online survey | Offer to promote the online survey via social media |
| 7-Aug-18 | NQ PHN | email | Newsletter | Shared in e-newsletter |
| 7-Aug-18 | Academic | email | Thanks | receipt of copy of pdf of online survey |
| 7-Aug-18 | Consumer | email | Thanks | receipt of copy of pdf of online survey |
| 7-Aug-18 | Consumer | email | Thanks | receipt of copy of pdf of online survey |
| 7-Aug-18 | Uni of WA | email | Online survey | Invitation to complete survey and share with networks. |
| 7-Aug-18 | Queensland Health | email | Face to face meeting | Requested a meeting to discuss. Meeting set for August 16th |
| 7-Aug-18 | NT Govt | email | Jurisdiction consultation | Meeting for NT. Online survey. Timelines. |
| 7-Aug-18 | Health Dept WA | email | Engagement | Request for guidance on how we would like them to be involved. |
| 7-Aug-18 | Health Dept WA | email | Online survey | Invitation to complete survey and share with networks. |
| 7-Aug-18 | Health Dept WA | email | Online survey | Invitation to complete survey and share with networks. Has agreed to share with networks. |
| 7-Aug-18 | Consumer | email | Online survey | Updated survey to remove reference to respiratory infection. |
| 7-Aug-18 | Health Dept WA | email | Online survey | Invitation to complete survey and share with networks. |
| 7-Aug-18 | Consumer | email | Registration | Involvement in process. She wrote on 26/7/18. Link to website page and survey sent. |
| 7-Aug-18 | Uni of WA | email | Online survey | Invitation to complete survey and share with networks. |
| 6-Aug-18 | LFA NSAP registration list (500) | email | Online survey | Reminder to complete the survey |
| 6-Aug-18 |  | email | PDF of online survey | Copy of online survey requested. |
| 3-Aug-18 | NT Government | phone meeting | Jurisdiction consultation | Meeting to discuss process and involvement. Will link with face to face meeting in October. |
| 3-Aug-18 | Health Dept WA | email | Contact person | Confirmation of contact people for WA |
| 3-Aug-18 | Cancer Council | email | Face to face meeting | Ask for meeting. |
| 2-Aug-18 | Indigenous Respiratory Outreach Care Program (IROC) | Phone and email | Stocktake | Clarification about involvement of ACAM in stocktake. Meeting request to discuss Action Plan. Also sent link to survey. |
| 2-Aug-18 | Murray PHN | email | E-newsletter | Electronic message to network. |
| 1-Aug-18 | Adelaide PHN | email | E-newsletter | Electronic message to network. |
| 1-Aug-18 | North Coast PHN | email | online survey/meeting | Responded to this email on 7/8/18 and sent link to online survey. |
| 1-Aug-18 | LFA | email | Online survey link | Forwarded email to Pulmonary Fibrosis Consortium members (excluding the members who are also Aus IPF Registry Steering Committee members. |
| 31-Jul-18 | Queensland Health | letter | Contact person | Senior Director, Strategic Policy and Legislation Branch nominated to meet with LFA. |
| 31-Jul-18 | NSW Rural Doctors Network | email | Marketing and comms | Will distribute through networks. Have passed on to Medical Advisor for response from RDN. |
| 30-Jul-18 | Coordinare (south Eastern NSW PHN) | email | E-newsletter | Electronic message to network. |
| 26-Jul-18 | ACT PHN | email | E-newsletter | Electronic message to network. |
| 26-Jul-18 | Lung Cancer Advocate | email | Survey response | Confirmation receipt |
| 26-Jul-18 | Australian Football League (AFL) | email | Survey response | Ideas for the action plan |
| 25-Jul-18 | E-newsletter | email | E-newsletter | Electronic message to network. |
| 25-Jul-18 | Safercare Victoria | email | Request for meeting | Request to share online survey and for a meeting to discuss priorities. Follow up email sent 9/8/18 |
| 25-Jul-18 | WA Health Dept. | email | Request for meeting | Request to share online survey and for a meeting to discuss priorities. |
| 25-Jul-18 | Queensland Health | email | Request for meeting | Request to share online survey and for a meeting to discuss priorities. |
| 25-Jul-18 | Tasmania Dept of Health and Human Services | Email and phone | Request for meeting | Follow up email sent 9/8/18. Meeting set up for August 30th |
| 25-Jul-18 | NSW Health | email | Request for meeting | Request to share online survey and for a meeting to discuss priorities. Follow up email sent 9/8/18 |
| 25-Jul-18 | ACT Health | email | Request for meeting | Meeting set up for August 23rd. |
| 25-Jul-18 | HealthInfoNet | email | Invitation to engage | Request to share EDM with networks |
| 25-Jul-18 | Qld Health Respiratory Clincial Network | email | Survey open | Request to share with network. Will share with network. |
| 25-Jul-18 | Agency for Clincial Innovation (NSW Health) | email | Survey open | Request to share with network. |
| 25-Jul-18 | NT PHN | email | E-newsletter | Electronic message to network. |
| 25-Jul-18 | LFA | email | Invitation to register | Forwarded email to Aus IPF-net |
| 25-Jul-18 | Cancer Council Australia | email | Media and comms. | Will share on social media and through newsletter. Sent follow up email on 3/8/2018 to set up meeting with Policy Advisor to talk about the Tobacco Strategy. He is the Chair of this committee. |
| 25-Jul-18 | Govt of WA (Dept of Health) | email | E-newsletter | Electronic message to network in WA sharing link to register |
| 24-Jul-18 | Northern Territory PHN | Phone | Face to face meeting | Arrange meeting for the NT. |
| 24-Jul-18 | Consumers Health Forum | email | Media and comms. | Will share on social media and possibly through newsletter. Consumers Shaping Health. |
| 24-Jul-18 | NT Govt. | email | Meeting request | Proposed process going forward |
| 24-Jul-18 | WA Respiratory Network | email | Meeting request | Proposed process going forward. To be included on agenda for WA Respiratory Network - August 13. |
| 24-Jul-18 | Federation of Ethnic Communities' Councils of Australia (FECCA) | email | Media and comms. | Request for collateral to engage members. |
| 24-Jul-18 | TSANZ | email | Media and comms. | Will share in enews. |
| 24-Jul-18 | Brisbane South PHN | email | Contact for engagement | General Manager Primary Health is nominated as contact person. |
| 23-Jul-18 | APNA | email | E-newsletter | Electronic message to network. |
| 23-Jul-18 | South Eastern Melbourne PHN | email | Contact for engagement | Response to letter and nomination of contact person. |
| 23-Jul-18 | ACT PHN | email | Contact for engagement | Response to letter and nomination of contact person. |
| 23-Jul-18 | TSANZ | email | Media and comms. | Request for collateral to engage members. |
| 23-Jul-18 | Western NSW PHN | email | Contact for engagement | Response to letter and nomination of contact person. |
| 20-Jul-18 | Brisbane South PHN | email | E-newsletter | Electronic message to network. |
| 20-Jul-18 | Northern Territory Government | letter | Contact person for NT | Director Chronic Conditions and Prevention is nominated as contact person. |
| 19-Jul-18 | Queensland Health | Phone and email | ATSI Health | Spirometry measures for this population and need for research into this area. Sent her link to register to receive the online survey. |
| 19-Jul-18 | Immunisation Coalition | email | E-newsletter | Electronic message to network. |
| 18-Jul-18 | Charles Sturt University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | Coordinare - South Eastern NSW PHN | email | Contact for engagement | Response to letter and nomination of contact person. |
| 18-Jul-18 | International Centre for Community Driven Research | email | Invitation to register for notifications | Request to share EDM with networks. Will share with networks. |
| 18-Jul-18 | The University of Western Australia | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | The University of New England | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | University of Canberra | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | The University of Notre Dame Australia | email | Invitation to register for notifications | Request to share EDM with networks. The Research Office will circulate internally as appropriate. |
| 18-Jul-18 | Edith Cowan University | email | Invitation to register for notifications | Request to share EDM with networks. Will circulate at ECU. |
| 18-Jul-18 | University of Tasmania | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | La Trobe University | email | Invitation to register for notifications | Request to share EDM with networks. Works with Advisory Group member Anne Holland who will coordinate distribution. |
| 18-Jul-18 | University of South Australia | email | Invitation to register for notifications | Request to share EDM with networks. Will share with colleagues and networks. |
| 18-Jul-18 | Consumers Health Forum | email | Request to share on social media. | Send out through Consumers Shaping Health newsletter and via social media. |
| 18-Jul-18 | Peter MacCallum Cancer Centre | email | Invitation to register for notifications | Will forward to the appropriate person |
| 18-Jul-18 | Australian Primary Care Nurse Association (APNA) | email | Invitation to register for notifications | Will put in e-newsetter. |
| 18-Jul-18 | Bond University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | University of Western Sydney | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | The University of Queensland | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | James Cook University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | Queensland University of Technology | email | Invitation to register for notifications | Request to share EDM with networks. Will circulate to QUT community. |
| 18-Jul-18 | The University of Adelaide | email | Invitation to register for notifications | Request to share EDM with networks. Will promote to research community. |
| 18-Jul-18 | Curtin University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | Charles Darwin University | email | Invitation to register for notifications | Request to share EDM with networks. Will support targeted circulation. |
| 18-Jul-18 | Deakin University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | University of the Sunshine Coast | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | Australian Catholic University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | Southern Cross University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | Monash University | email | Invitation to register for notifications | Request to share EDM with networks. Has disseminated to Monash research community for input. |
| 18-Jul-18 | The University of Sydney | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | Flinders University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | University of Southern Queensland | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | Macquarie University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | The University of Newcastle | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | Swinburne University of Technology | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | University of Wollongong | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | RMIT University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | University of Technology Sydney | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | The University of Melbourne | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | Murdoch University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | University of Ballarat | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | CQUniversity | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | The Australian National University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | The University of New South Wales | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | Griffith University | email | Invitation to register for notifications | Request to share EDM with networks. Will do. |
| 18-Jul-18 | Victoria University | email | Invitation to register for notifications | Request to share EDM with networks |
| 18-Jul-18 | LFA | email | Invitation to register | Forwarded email to Clinical Committees for Rare Lung Disease, Pulmonary Hypertension and Young Lungs. Patient Committees for Young Lungs Parent Advisory and Pulmonary Fibrosis Patient Advisory. External Committees - Pulmonary Hypertension Assoc of Australia and Pulmonary Hypertension Network Australia. |
| 18-Jul-18 | Brisbane South PHN | email | Contact for engagement | Response to letter and nomination of contact person. Published in their newsletter on 27/7/18. |
| 17-Jul-18 | Rural Health West | email | Invitation to register for notifications | Request to share EDM with networks. Will circulate in bulletin in early August |
| 17-Jul-18 | Woolcock Institute | email | Invitation to register for notifications | Request to share EDM with networks. Will share with networks. |
| 17-Jul-18 | Northern Territory PHN | email | Invitation to register for notifications | Request to share EDM with networks |
| 17-Jul-18 | The Pharmaceutical Society of Australia (National Office) | email | Invitation to register for notifications | Distributed to state/territory branches and communications team. |
| 17-Jul-18 | TAZREACH | email | Invitation to register for notifications | Request to share EDM with networks. Will share with networks. |
| 17-Jul-18 | Rural Doctors Workforce Agency | email | Invitation to register for notifications | Request to share EDM with networks. Will share in weekly enews. |
| 17-Jul-18 | LFA | email | Invitation to register | Forwarded email to Aus IPF Registry Steering Committee (15) and 2 research fellows. Will ask committee to forward to AUS IPF-net. |
| 17-Jul-18 | NSW Rural Doctors Network | email | Invitation to register for notifications | Request to share EDM with networks. Will discuss dissemination with team and advise. |
| 16-Jul-18 | CheckUp | Face-to-face | Link with Outreach services | Connecting with needs identified through outreach service programs. Request for other state contacts of MSOAP. Will share with networks via newsletter. |
| 16-Jul-18 | Exercise & Sports Science Australia (ESSA) | email | Invitation to register for notifications | Will share with network. |
| 16-Jul-18 | Immunisation Coalition | email | Invitation to register for notifications | Request to share EDM with networks |
| 16-Jul-18 | Health Consumers Forum | email | Invitation to register for notifications | Request to share EDM with networks |
| 16-Jul-18 | WA Health Dept. | email | Request for meeting | Follow up from official correspondence. Contacts nominated. Offered to publish in special bulletin to those with an interest in respiratory. |
| 16-Jul-18 | TSANZ | email (2) | Framework feedback | Board member feedback on current draft framework |
| 16-Jul-18 | Adelaide PHN | Phone and email | Distribution | Population health team to complete online survey on behalf of organisation. Will share EDM in newsletter. |
| 13-Jul-18 | Australian College of Rural & Remote Medicine (ACRRM) | Email | Invitation to register for notifications | Indicated that GM for Quality and Safety would be in contact |
| 13-Jul-18 | Adelaide PHN | email | Invitation to register for notifications | Will share EDM with Steering Commitee on the Adelaide Respiratory Health Project, practices on health care homes trials, care connections program, members of the chronic conditions collaborative. |
| 12-Jul-18 | LFA communications list | email | Reminder to register for notifications |  |
| 12-Jul-18 | LFA | email | Invitation to register for notifications | Forwarded email to Lung MDTs (165) and ANZ-LCNF (9). |
| 12-Jul-18 | NT Health | Phone and email | Invitation to register for notifications Info session in Darwin Oct 25 | Request to share EDM with networks. Will share with networks |
| 12-Jul-18 | The Pharmaceutical Society of Australia (National Office) | email | Invitation to register for notifications | Request to share EDM with networks |
| 12-Jul-18 | Queensland Aboriginal and Islander Health Council (QAIHC) | email | ATSI engagement | Request for meeting to discuss consultation |
| 12-Jul-18 | The Pharmacy Guild of Australia - National Secretariat | email | invitaton to register for notifications | Will share in Forefront newsletter on 25 July |
| 12-Jul-18 | Central Australian Aboriginal Congress (CAAC) | email | ATSI engagement | Request for meeting to discuss consultation |
| 11-Jul-18 | CheckUp | email | Potential link with consultation group. | Request to share EDM with networks |
| 11-Jul-18 | Australian Respiratory Council (ARC) | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | Exercise & Sports Science Australia (ESSA) | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | CheckUp | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | Australian Primary Care Nurse Association (APNA) | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | The Pharmacy Guild of Australia - National Secretariat | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | Federation of Ethnic Communities' Councils of Australia (FECCA) | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | Australian Association of Consultant Pharmacy (AACP) | email | Invitation to register for notifications | Request to share EDM with networks. Will put in newsletters. |
| 11-Jul-18 | Council on the Ageing (COTA) Australia | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | The Society of Hospital Pharmacists of Australia (SHPA) | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | Palliative Care Australia Inc | email | Invitation to register for notifications | Request to share EDM with networks. Offered to share in newsletter and affiliate organisations, i.e. PCNA, ANZPM, PAPCANZ. Also offered support from Clinical Advisor in Palliative care. |
| 11-Jul-18 | Australian College of Rural & Remote Medicine (ACRRM) | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | Council on the Ageing (COTA) Queensland | email | Invitation to register for notifications | Request to share EDM with networks. Will bring to the attention of older Queenslanders. |
| 11-Jul-18 | Asbestos Safety and Eradication Agency | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | Asthma Australia | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | Cystic Fibrosis Australia | email | Invitation to register for notifications | Request to share EDM with networks. Will share with CF community and state offices. |
| 11-Jul-18 | The Society of Hospital Pharmacists of Australia (SHPA) | email | Invitation to register for notifications | Offered to share in weekly eNews (5,500 recipients). Will promote draft plan in October too. |
| 11-Jul-18 | Rural Doctors Association of Australia | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | Australian and New Zealand Society of Respiratory Science Ltd (ANZSRS) | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | WAPNA | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | Cancer Council Australia | email | Invitation to register for notifications | Request to share EDM with networks |
| 11-Jul-18 | The Pharmaceutical Society of Australia (NSW Branch) | email | Invitation to register for notifications | Request to share EDM with networks. |
| 11-Jul-18 | Australasian Sleep Association | email | Invitation to register for notifications | Request to share EDM with networks. Will put in newsletters. |
| 11-Jul-18 | Cancer Australia | email | Invitation to register for notifications | Request to share EDM with networks. Offered option to meet to discuss. |
| 11-Jul-18 | The Royal Australian College of General Practitioners (RACGP) - National Office | email | Invitation to register for notifications | Request to share EDM with networks |
| 10-Jul-18 | Qld Health Respiratory Clincial Network | email | Invitation to register for notifications | Request to share EDM with networks |
| 10-Jul-18 | TSANZ | email | Invitation to register for notifications | Request to share EDM with networks |
| 9-Jul-18 | NSW Agency for Clinical Innovation | email | Invitation to register for notifications | Engagement process raised after KH met with Agency. |
| 9-Jul-18 | NAC | email | Invitation to register for notifications | Offer to share EDM with networks |
| 9-Jul-18 | SA Govt. | Letter | Receipt of letter | Advice that letter received and is being considered. |
| 9-Jul-18 | Katherine Hospital | email | Invitation to register for notifications | Respiratory and General Physician - suggestion to sign up for mailing list. |
| 6-Jul-18 | NT Govt. | email | Request for current framework | Preparation of response to LFA request. |
| 5-Jul-18 | PHNs | Letter | Process for engagement | Provided copy of current framework. Advised of dates for online surveys - 1. ID goals and priorities, 2. Feedback on draft plan |
| 5-Jul-18 | Qld Govt. | Phone and email | Request for current framework | Preparation of response to LFA request. |
| 5-Jul-18 | WA Health Dept. | Email | Contact for engagement | Provided contact, Director of Health Networks, Clinical Leadership and Reform, Clinical Excellence Division of WA Health |
| 4-Jul-18 | Darling Downs and West Moreton PHN | Email | Invitation to register for notifications | Request to share EDM with networks |
| 28-Jun-18 | WA Health Dept. | Email | Process for engagement | Will meet with networks regarding WA Health input. Requested DOH contact. |
| 26-Jun-18 | LFA Airwaves newsletter | Email | Invitation to register for notifications | 94 clicks on article on Nat Strat Action Plan in Lung Conditions |
| 21-Jun-18 | LFA communications list | email | Invitation to register for notifications | Open rate 29.7% |
| 15-Jun-18 | State Health Depts. | Letter | Process for engagement | Request for departmental contact person for liaison. Set up a meeting to discuss framework and process. |
| 15-Jun-18 | State Govts. | Letter | Process for engagement | Advice on consultation approach. Outline of plans for development of action plan. |
| 20-Mar-18 | LFA communications list | email | Announcement of funding | Open rate 34.74% |