

## **Breathing Easier Project**

HCCA Project on Improving Care for People with Chronic Obstructive Pulmonary Disease (COPD)

**Final Report** 

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## Introduction

#### **Health Care Consumers' Association**

The **Health Care Consumers' Association (HCCA)** is a health promotion agency and the peak consumer advocacy organisation in the Canberra region. HCCA provides a voice for consumers on local health issues and provides opportunities for health care consumers to participate in all levels of health service planning, policy development and decision making.

HCCA involves consumers through:

- consumer representation and consumer and community consultations;
- training in health rights and navigating the health system;
- community forums and information sessions about health services; and
- research into consumer experience of human services.

HCCA is committed to consumer centred care<sup>1</sup> as a foundation principle in all its work and to promoting consumer centred care across the health system, within government and across the ACT community. Consumer centred care meets the physical, emotional and psychological needs of consumers, and is responsive to someone's unique circumstances and goals.<sup>2</sup>

#### **Scope of the Project**

HCCA commissioned a rapid response research project conducted over a 3-4 month period, to guide the development of a consumer centred and integrated model of COPD care for the ACT. The research is intended to:

- look at the current approach to COPD care in the ACT and best practices used in other places in Australia and overseas;
- interview ACT people and their carers about their lived experience with COPD and their care during the past 3 years in particular - what works, what doesn't and what could improve their care;
- draw on the experiences of community organisations which advocate for people with COPD; and
- use the ideas and experiences collected through this project to develop recommendations for improving COPD care in the ACT.

The report will be made publicly available after completion. It is hoped that it will influence the future development of COPD services to better reflect the needs of people with COPD and the needs of their carers and families.

#### **Interim and Final Report**

An interim report was prepared for HCCA. It looked at what is known about Chronic Obstructive Pulmonary Disease (COPD) and ACT population-based data about the condition. It also looked at best practice ways that are already known to ensure that people with COPD have the best quality of life they can and the best evidence-based care throughout their journey with COPD. It then described the existing arrangements in the ACT and some of the preliminary views of consumers and providers about the strengths and weaknesses of current arrangements.

This information has been included in the first 5 chapters of the Final Report. This allows the Final Report to stand alone. and the Final Report also explores additional information and research within the framework of the COPD-X Guidelines. These define up-to-date Australian best practice care and treatment for people with COPD, based on international and national expertise. The quality and importance of these Guidelines and their history are discussed in Chapter 3. The key recommendations of COPD-X are used as the framework to provide recommendations on how a best practice, ACT-wide system could be established to ensure the best lives possible for people with COPD.

Discussions with key stakeholders – consumers, carers, advocacy groups, doctors and nurses - show a high degree of consistency about what people see as working well and what is not. Generally, there was significant enthusiasm for improving the arrangements in the direction of best practice and more integration. This provides a strong basis for moving forward together.

#### **Acknowledgements**

HCCA would like to thank the consumers and carers, doctors, nurses, other health professionals and administrators, and advocacy groups who have spoken to Dr Fiona Tito Wheatland in the course of this work. We also thank HCCA members who provided linkages with community organisations and provided enthusiastic support for the project, especially the Masters Thesis work of Caroline Polak Scowcroft on public narratives on COPD from the Internet.<sup>3</sup>

We hope that this Breathing Easier Project Final Report provides an insight into the experiences of current COPD arrangements for consumers, carers and providers described to Fiona. The thoughtful input and collaborative approach of almost all contributors provides a great foundation to improve the process and outcomes for people with COPD.

Some of our Canberra-based services and organisations also work with people outside the ACT community. People from surrounding areas of NSW who come to the ACT when they require hospital care or specialist care have not been the focus of this project, but in some areas, they had experiences in their home state which may be of assistance here. It is also hoped that the recommendations will resonate for this wider population and organisations like the Primary Health Network and practitioners who work across jurisdictions. Similarly, some services used by consumers are far distant and accessed through computers and telephones, but they are important parts of the system here and we acknowledge their assistance.

Given the relatively small number of participants in this research, we have chosen to maintain their anonymity as much as possible. People may recognise themselves and their words. Some providers, consumers and carers can feel vulnerable about expressing their views about the services they work in or use. We wanted to ensure that people felt safe being honest, even where they had criticisms or suggestions for change. Not all participants required this, but it is difficult to identify some and not others in small jurisdictions like the ACT, so we opted to as much as possible anonymise contributions. We are deeply grateful for all your help, information and honesty, as well as your imagination and compassion to each other.

### **Executive Summary**

The research and interviews undertaken as part of this HCCA project revealed a system which had many parts of an effective framework in place, but poor linkages. The Overview at the beginning of Chapter 6 below summarises this.

The research and interviews for this project showed that many parts of the framework are there, but they are like a partly constructed building. There are lots of rooms there – but finding the way between them is not easy and people with COPD often fall through the holes. Providers also may not know where to go – and the architect seems to have gone to the Bahamas in the middle of the construction. There are also key elements like halls and paths that could have linked things together but don't.

The history of reform to create person centred health care for people with one or more chronic conditions is set out in Appendix A of this Report. It has been one of glacially slow progress, with many trials and changes to systems to address identified problems, but without durable improvements in many cases. As the research and experiences of consumers and providers show, there remains a lot to be done to deliver on the often repeated vision of an integrated, person centred health and support system.

Political and professional commitment does exist in the ACT to achieve this goal and we believe that the pillars of a framework to achieve this are sound. These include:

- the existence of the very up-to-date COPD-X guidelines, set out in Lung Foundation Australia's *The COPD-X Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease* (the COPD-X Plan) produced annually and the complementary support and educational materials, advice and services available from Lung Foundation Australia;
- the increased policy, funding and professional interest in ensuring that the health systems and health professionals can deliver properly coordinated and integrated care that is patient centred;
- the growing utility of My Health Record to connect a consumer's health information across a range of health services;
- the greater availability of practice nurses and allied health services through general practice planning and Medicare funding;
- the existence of the Capital Primary Health Network to assist with communication and training across the broader primary care landscape;
- the extensive experience and lessons learned over the past 3 decade as we have piloted and trialled coordinated and integrated care practices, especially in chronic conditions; and
- the various national frameworks and agreements set out in Appendix B, which provide useful support for the reforms needed to deliver better care to people with COPD and other chronic conditions.

The recent ACT budget decision, announced in October 2021, to introduce a Patient Navigator Service for people with complex and chronic care needs provides impetus and funding to build on the framework pillars set out above. The initial scoping for the full service provides an excellent opportunity to address many of the issues raised in this Report. The continued commitment of the ACT Government to nurse-led Walk-In Centres provides another way to support improved service coordination for people with COPD, to reduce their need for hospital services and to provide information to assist them in self-management.

These are all elements which can help shape an excellence framework for innovation and reform for ACT people with COPD. The availability of gold standard clinical guidelines, like the COPD-X, for other chronic conditions could result in a broader model of care for people with one of more chronic conditions in the ACT.

Our research and its comparison between what exists in the ACT and what should be in place to meet the COPD-X standards, shows we have a way to go. Much still remains to be done to ensure people have prompt and timely access to appropriate COPD health assistance, include early diagnosis, active and evidence-based care planning and treatment, and better management to prevent exacerbations and hospitalisations. Collection of useful, timely data is also crucial to inform our evidence base and planning.

There are extensive resources available in the broader community, which can supplement the specific Lung Foundation Australia material. These resources include exercise classes, social and educational sessions which can address people's social isolation, and options for in-home support services to help people if their activities of daily living are impacted by their COPD. However, people often don't know about them. Having a single place to go for information would be a welcome development for professionals and consumers alike.

The Canberra Lung Life Support Group is a valuable point of information for consumers. However, it is under-utilised and under-funded. Assistance should be provided to help them better achieve their potential as a voice for consumers and families affected by COPD and as a source of up-to-date information. The health system also has an important role in providing up-to-date information about what support and treatment is available in the ACT. Services outside the medical system can support the wellbeing of people with COPD and other chronic conditions. Timely and affordable access to these services and health services are important to ensure consumers are supported in their health and life journey as seamlessly as possible. This is not currently the case.

There is also work to be done to remove the stigma people are faced with when they have a chronic lung condition. The term "lifestyle disease", which is applied to many chronic conditions, is often used in a disparaging and blaming manner by people in the community and, sadly, sometimes by health professionals. This can lead to people feeling shamed and isolated when they and their families are living with the serious and often irreversible impacts of chronic conditions. Kindness and compassion, as well as practical assistance, is the only just and therapeutic approach to the impact of chronic conditions on people's wellbeing, longevity and need for care and support.

### **Recommendations for Action**

#### **Care coordination & Systemic integration**

Improvement of the care for people with COPD cannot be undertaken in only one functional area of the health system and it must include areas outside health care. Reforms must be implemented across traditionally siloed functional areas, with the needs of people with COPD as the pivotal centre.

Some of the earlier coordinated care models recognised the need to break out of siloes to better meet patient needs. The last two decades also saw the development of different collaboratives in health care as a means of facilitating better coordination both here<sup>4</sup> and overseas<sup>5</sup>. Similar processes are currently being undertaken in NSW Health through their Collaborative Commissioning initiative, which also engages Commonwealth and State funding sources to deliver better health outcomes for consumers.<sup>6</sup>

Collaboratives provide a place where everyone is "inside the same tent" – consumers and carers primary care providers such as general practitioners, pharmacists and allied health providers; tertiary inpatient and outpatient services and specialist clinicians; community organisations; and government(s). They work together to develop the best models of care for consumers that is evidence based, accessible, effective and efficient. They then work further to implement the model(s), collect data and learn in rapid quality improvement cycles which are responsive and timely. Where it becomes apparent there is a needs gap, ways to meet these can be tried and tested as the initiative goes along.

Based on the best practice in COPD care outlined in the COPD-X Guidelines, a collaborative model would start with a strong evidence base about what was needed. There was general support from all people who participated in this research for a mechanism for getting everyone around the table and working out how to work better together to meet the needs of people with COPD.

We have sixteen recommendations for action:

- A Chronic Care Collaborative should be formed as soon as possible) to develop and operationalise a model of care (or more than one model if appropriate) to best serve the needs of people with COPD. Any model(s) of care should be, based on the COPD-X Guidelines. This collaborative should include both health related Directorates; consumers, carers and people with COPD; as well as representatives of all professional groups involved in providing services (including the Primary Health Network, Hospital and Outpatient respiratory services, general practitioners and relevant health and community services)..
- 2. The Collaborative should determine ways a care team can work effectively across primary, tertiary and allied health care and the community. The aim is to have a model which shares information to ensure a person with COPD gets the best care at the right time and can manage their own condition confidently. The model should be designed toto best utilise the skills of the different members of the team and to provide care in the most appropriate way for each consumer using a range of service delivery methods. These could include: telehealth, home visiting, after hours call assistance, emails or text messaging, using

pharmacies or practice nurses to monitor appropriate metrics of wellbeing or to monitor health.

3. The Collaborative's work should feed into the scoping work for the Patient Navigator Service to ensure that the best outcomes for consumers are achieved.

#### **Best Practice Care**

- 4. The Collaborative should ensure models of care reflect evidence-based best practice outlined in the COPD-X Guidelines:
  - Primary care day-to-day coordination by teams including a general practitioner, practice nurse and administrative person to assist with organising coordination across a team;
  - b. Excellent self-management education and skills development options;
  - c. Education for primary care in case identification and monitoring processes for people who are diagnosed with COPD;
  - d. Good care planning processes including: medication reviews where needed by pharmacists; access to full lung function testing when necessary; specialist advice for GPs to help management in general practice; and to provide expert advice to consumers in a timely manner;
  - e. Easy access to advice in and out of hours to help people stay at home rather than presenting to hospital;
  - f. The use of other allied health professionals to assess people with COPD to prepare them to undertake regular exercise; and
  - g. Self-management skills development to allow consumers greater control over the management of their condition and its progression.
- 5. The Collaborative should address barriers to best practice care, including those identified in the research for this project.
  - a. Pulmonary rehabilitation should be made available on diagnosis, after an exacerbation and at any time that the patient's age or condition has altered sufficiently for them to benefit from revised or renewed pulmonary rehabilitation.
  - b. Entry to pulmonary rehabilitation should be by referral from a general practitioner, or relevant specialist where a patient has a co-existing chronic condition, for consumers whose FEV scores derived from spirometry indicate COPD.
  - c. Where oxygen therapy is required, based on the COPD-X Guidelines, supply should be adequate to allow consumers to participate in out of home activities to facilitate them remaining as active as possible for as long as possible. This could be by permitting access to sufficient cylinders or using technology such as portable oxygen concentrators.
  - d. Provision of sufficient oxygen to meet the evidence-based guidelines of 18 hours per day supplementation and sufficient hardware (such as tubing) for people to move easily around their housing.

- e. Health professionals and consumers need to be able to discuss experiences of stigma and remove these from the care relationship.
- 6. Best practice care models need to be considered and developed, where appropriate, for specific groups in the ACT community, which may have different needs. This includes, for example, Aboriginal or Torres Strait islander people, people with language or cultural diversity, people with socio-economic disadvantages or those with trauma experiences. The Collaborative should engage directly with any identified population groups in co-design processes to try and improve the outcomes for such groups, which may be marginalised in other processes. Options such as circle conversations or yarning circles, where all voices are heard respectfully, should be used.

#### **Care planning and Self-management**

- 7. Recognising that care planning and self-management are complementary and need to be consistent with each other, all people with COPD should have an agreed COPD action plan, which they hold and which is placed on their My Health Record and in the records of all members of their treating team.
- 8. High quality information on all aspects of COPD care and management needs to be available to health professionals, consumers and carers, to facilitate a shared understanding for care planning, management of exacerbations and to improve their shared knowledge of treatments and options for non-medical interventions.
- 9. Consumers should be assisted to look at their broader life goals or aspirations and to set these down and review them from time to time. These can be shared with their care team to better facilitate their capacity to do the things they want to do.
- 10. The Canberra Lung Life Support Group should receive assistance to upgrade their web presence and to support the development of a more extensive face-toface consumer focused education program for people with lung conditions. These two options would expand information and health literacy assistance to more people with COPD in the Canberra community.

#### Data collection and analysis, including evaluation

- 11. Data on the incidence of COPD in the ACT community needs to be available and better systematic data collected on their experiences and outcomes. This should include data on: delays in obtaining care, problems they experience, solutions and work-arounds that they have used to overcome gaps or short-comings in service availability, and gaps in services.
- 12. The Collaborative should review the outcomes of the Health Care Home Evaluation expected out in late 2021 for any useful ideas from that work.
- 13. The Collaborative should consider whether any of the chronic care innovations identified by the Productivity Commission in their 2021 case study document may be suitable for use in the ACT.
- 14. The Collaborative should determine whether there are other opportunities relating to funding and assistance which might be available under the National Health Reform Agreement for improved chronic care management. These are discussed in Appendix B and could assist in achieving a better system for ACT people with

COPD and other chronic conditions. It would also be useful to explore the NSW Collaborative Commissioning arrangement with the Commonwealth Government, as this might provide a new funding model for care for people with complex or chronic care needs across primary and tertiary care systems.

15. The Collaborative should establish an evaluation strategy for its work and censure data is collected to measure its effectiveness in relation to consumers, providers and the broader community and health system.

#### Training

16. The Collaborative should ensure that there is adequate training available for spirometric testing in primary care settings. They will need to establish standards for training, given the current variety of course durations and training providers that are entering the market.

## Chapter 1: What is Chronic Obstructive Pulmonary Disease?

#### **Definitions and international prevalence**

Chronic Obstructive Pulmonary Disease (COPD) is defined in the COPD Guidelines of Lung Foundation Australia as:

a preventable and treatable disease with some extrapulmonary effects that may contribute to the severity in individual patients. Its pulmonary component is characterised by airflow limitation which is not fully reversible. The airflow limitation is usually progressive and associated with abnormal inflammatory response of the lung to noxious particles or gases.

More simply, Lung Foundation Australia<sup>7</sup> describes it as an umbrella term for a group of lung conditions, which include emphysema, chronic bronchitis and chronic asthma, however, not all cases of asthma involve COPD. COPD and asthma overlap in about 20% of people with asthma. The characteristics which seem to be definitive of COPD are that the condition is progressive, involves narrowing of the bronchial tubes in the lungs, makes it difficult to breathe, and involves an inflammatory response in the lungs to particles that are breathed in. Lung Foundation Australia also notes that sometimes air becomes trapped in the lungs, causing feelings of breathlessness.

The three main symptoms experienced by people with COPD are breathlessness, cough and sputum production. Significant breathlessness (also called "dyspnoea") often has an impact on a person's wellbeing and daily life. Chronic cough and sputum result in increased risk of exacerbations (such as a lung infection that makes their COPD worse either temporarily or permanently).<sup>8</sup> Management of these symptoms and prevention of exacerbations are discussed in Chapter 7 of this report.

COPD is called a chronic condition because it is long term and is not curable. However, there are ways to reduce the impact of the condition, particularly if someone is diagnosed early and is able to slow the rate of progression. Most of the interventions that slow progression also improve the person's quality of life.

Internationally, the Global Initiative for Chronic Obstructive Lung Disease (GOLD) stated that COPD is one of the top three causes of death across the world, with 90% of these occurring in low or middle income countries.<sup>9</sup> It is difficult to compare data between countries because different conditions are sometimes included under the COPD umbrella. The 2020 GOLD Report noted that more that 3 million people died of COPD in 2012, accounting for 6% of all deaths.<sup>10</sup>

The main risk factors for developing COPD across the world are believed to be:11

- exposure to cigarette smoking, either directly<sup>12</sup> or indirectly through passive smoking;<sup>13</sup>
- air pollution where you live or work, including diesel fumes, dust from animal feeds, dusts from spinning, weaving and knitting cotton or silk, mineral dust and other dusts, vapours, fumes or gases;<sup>14</sup>

- indoor open fires, especially when used for cooking where there is poor ventilation;<sup>15</sup>
- working and living where there is gas, dust, chemical fumes or smoke;<sup>16</sup>
- under-development of the lungs prenatally or in childhood caused by illness, prematurity or exposure to many of the above irritants;<sup>17</sup>
- genetic factors, including Alpha-1 antitrypsin deficiency;<sup>18</sup> and
- previous or co-existing disease which can lead to lung damage, such as tuberculosis or HIV.<sup>19</sup>

In Australia, the most important risk factor for developing COPD is considered to be cigarette smoking.<sup>20</sup> This does not mean that non-smokers will not develop COPD or that all smokers will develop COPD:

about half of all smokers develop some airflow limitation and 15 to 20% will develop clinically significant disability.<sup>21</sup>

However, if someone develops COPD, continuing to smoke will result in a steady decline in lung function. Stopping smoking may result in minimal improvement in lung function, but it will slow the rate of decline in function and the development of disability.<sup>22</sup>

A key measure of the existence and severity of COPD is the Forced Expiratory Volume (FEV) value –. The most common measure is the FEV1, which is the amount of air you can force from your lungs in one second. This is measured using a spirometer (a machine a patient blows into) or pulmonary function test. The COPD-X Guidelines state that:

There is a close relationship between the amount of tobacco smoked and the rate of decline in forced expiratory flow in one second (FEV<sub>1</sub>), although individuals vary greatly in susceptibility. Around half of all smokers develop some airflow limitation, and 15 to 20% will develop clinically significant disability. ... In susceptible smokers cigarette smoking results in steady decline in lung function, with a decrease in FEV<sub>1</sub> of 25-100mL/year. While smoking cessation may lead to minimal improvement in lung function, more importantly it will slow the rate of decline in lung function and delay the onset of disablement. At all times smoking cessation is important to preserve remaining lung function.<sup>23</sup>

Strong regulatory control of air pollution, controls around industrial exposures to dust, and low levels of diseases like tuberculosis, mean these causes of COPD are less significant in Australia compared to other nations. However, the COPD-X Plan guidelines notes that "COPD almost always arises from a gene environment interaction".<sup>24</sup>

In the consumer research, people with COPD talked about coming from families where there was a high prevalence of COPD. One consumer noted that her parents, grandparents and siblings had all either died from or currently had COPD. In one case, a consumer who had nursed her parents who had both died of COPD, went into her doctor and said, "Please test me, I believe I have COPD." This emphasises the importance of General Practitioners and Respiratory Physicians seeking a history of familial conditions, which could facilitate early identification.

#### **COPD** and co-existing conditions

COPD can also be associated with other conditions. These areoften called "co-morbidities" in the medical literature, but are referred to as "co-existing conditions" or "co-existing chronic condition" in this report. These commonly include cardiac conditions, stroke, diabetes, and depression, but also anxiety, obesity and osteoporosis. People may therefore be taking several medications ("polypharmacy") which can create problems associated with conflicting drug interactions. People often also report mobility problems independently of any shortness of breath associated with their COPD (for example from arthritis). The interactions between these conditions can make attaining optimal overall health more complicated. The COPD-X Guidelines refer to this as "multimorbidity", where:

two or more chronic medical conditions ... may or may not directly interact with each other within the same individual. Multimorbidity is the norm rather than the exception in older primary care patients. Managing patients with multimorbidity effectively involves taking a patient-centred approach to balancing multiple, and at times, competing priorities. Both comorbid chronic respiratory conditions and comorbid psychiatric disorders have been found to be associated with a higher risk of frequent ( $\geq$  2 per year) exacerbations.<sup>25</sup>

For people with co-existing conditions, the role of primary care and the person's general practitioner is even more important for consumer centred care, as different body systems may be being treated by different specialists. This is recognised in the Royal Australian College of General Practitioners (RACGP) aged care clinical guide known as the Silver Book.<sup>26</sup> This book deals with people who are 65 and older and notes that:

the prevalence of multimorbidity is reported to be in the order of 25%, and the prevalence has been found to increase with increasing age, socioeconomic deprivation and the female gender. As physical conditions increase, the likelihood of a mental health condition increases.<sup>27</sup>

One of the consequences for people with co-existing conditions is that they may have some of the same symptoms as COPD, but the cause may be different. COPD-X noted that co-existing conditions can contribute to both underdiagnosis and to misdiagnosis of COPD and that spirometric testing is particularly important for diagnosis of COPD by either physicians<sup>28</sup> or general practitioners.<sup>29</sup>

# **Emerging issue: Climate change related air quality issues**

The importance of bushfire smoke is an emerging concern, given the experience of smoke from bushfires in 2019-2020 and the potential of similar events in a climate of global warming. Air quality in parts of Australia was the poorest in the world during some of that period and was hazardous for a longer period.<sup>30</sup> For people with COPD, it may be that smoke from fires could emerge as an important contributor to existing

lung conditions. Longer term, it may be that air pollution from fires could contribute to the development of COPD if they become a regular part of our climate.<sup>31</sup>

# **Emerging issue: E-cigarettes and smoking using a hookah or bong**

E-cigarettes are often seen by young people as a less harmful way of "smoking" nicotine, and that people who are already smoking cigarettes may use them for smoking cessation. The evidence on E-cigarettes as a "quit" device is far from clear but the Australian Department of Health has stated that it may be an even more addictive mechanism for delivery of nicotine than ordinary cigarettes and might lead to people taking up cigarette smoking.<sup>32</sup>

For some years, E-cigarettes containing nicotine have been prohibited for sale in Australia. in October 2021, the Australian Therapeutic Goods Administration (TGA) determined that the importation of nicotine solutions for E-cigarettes will be treated as a prohibited import, unless the patient has a prescription from a doctor stating that it is for smoking cessation. The person will also have to get an import approval and have to acquire the drug through a pharmacist. An Australian pharmacist will also be able to dispense or compound a nicotine vapour compound for use in E-cigarettes for a named person holding a prescription.<sup>33</sup>

There have been shown to be significant risks in an unregulated market, which fails to look at quality and what the inhaled substance is made from. For example, the United States (US) Centre for Disease Control and Prevention issued a warning about an outbreak of lung injury associated with the use of E-cigarette or vaping products (called EVALI) which, by 18 February 2020, had seen 68 deaths and 2,807 hospitalised consumers. Investigations showed that in the US, most deaths and hospitalisation were associated with a Vitamin E addition to the inhalant. 82% of the products contained THC (the active ingredient in cannabis), and 57% contained nicotine.<sup>34</sup> More generally, the CDC has issued a warning that E-cigarettes involve significant risks for children, teenagers and young adults,<sup>35</sup> and can lead to addiction to nicotine and negative impacts on developing brains up to about age 25 years. Research shows that using nicotine in adolescence can harm the parts of the brain that control attention, learning, mood and impulse control. The US Surgeon General has produced a detailed report on the risks of these devices for young people.<sup>36</sup>

People who smoke hookahs<sup>37</sup> or bongs<sup>38</sup> containing tobacco or nicotine and cannabis, can also suffer lung damage and illness which may lead to COPD, especially with heavy use. The issue has not been well studied due to secrecy about use when cannabis use was illegal. More research is needed into cannabis smoking (rather than a mix of cannabis and tobacco), but the current hypothesis is that particulate damage is still likely to occur, even without tobacco being present.<sup>39</sup> However, some research is showing that the damage may not be a precursor to COPD but to different conditions. This will need to be considered as the smoking of cannabis become more widespread, and where people are smoking both cannabis and tobacco.

The Australian Institute of Health and Welfare (AIHW) reports that young people aged 18-24 in Australia have lowered their daily use of cigarettes by more than half between 2001 and 2019. However, the proportion of young people aged 18-24 who

have experimented with E-cigarettes increased from 19% to 26% between 2016 and 2019. Cannabis use over the previous 12 months in the 18-24 year age group was around 25% and this remained stable from 2016 to 2019.<sup>40</sup> Better data on long term lung effects are important in planning for health care needs in the future.

## Chapter 2: Who is affected by COPD?

#### Australia wide data

The Australian Institute of Health and Welfare\_(AIHW) produced a Report on 25 August 2020 which provided the most current Australian data on COPD,<sup>41</sup> gathered from a range of sources.<sup>42</sup> The data is for Australia as a whole. The data shows that:

- COPD was the 5th leading cause of death in Australia in 2018 at 4.5% of deaths;
- COPD is almost twice as frequent in the lowest socio-economic group compared to the highest 7.1% compared to 3.6%;
- COPD is between 2 and 3 times more prevalent in people over 75, compared to people 45-54 - men 2.0% compared to 7.3% and women 2.5% compared to 5.9%;
- Self-assessed health of people with COPD is significantly lower than people without COPD;
- People with COPD experience psychological distress at a much higher level than people without COPD, with 36% of people with COPD experiencing high or very high psychological stress compared to 12% of those over 45 without COPD;
- People with COPD often experience pain to a greater extent than people without COPD – 62.5% of people with COPD have moderate or high pain and only 8.9% experience no pain, while 33.3% of people without COPD experience these higher levels of pain and 27% experience no pain; and
- COPD is more common among Aboriginal and Torres Strait Islander people, who have higher hospitalisation and death rates from COPD than non-Indigenous Australians. Indigenous Australians are also more likely to die younger.<sup>43</sup> The recently released Fourth Australian Atlas of Health Care Variation states that the rate of COPD for Aboriginal and Torres Strait Islander people was 4.8 times higher than the rate for other Australians.<sup>44</sup>

COPD is a condition of gradual onset and is infrequent in people under 45. The lung damage which gives rise to COPD is cumulative over many years. Even though smoking rates over time have declined significantly,<sup>45</sup> there is a clear lag from the time of reduction in smoking behaviours and a reduction in deaths for COPD.

The downward slope of the incidence of COPD because of smoking cessation is a positive health trend. However, the reduction in smoking is not even across Indigenous or non-Indigenous communities in Australia. Higher levels of smoking occur in lower socio-economic areas, in people in remote and very remote areas, in people who are not in employment (either unemployed or not able to work) and in people with lower levels of education.<sup>46</sup>

Even with the decline in smoking, the continuing survival of a larger proportion of the population to a greater age means that COPD and other lung conditions associated with older age and cumulative damage will be present in the community, probably in increasing numbers, for some time.

This issue was raised by a clinician in the research interviews. The proposition put was that while the number of people with smoking-related COPD decreased, there

would still be a consistent level of people whose lung condition arose from other causes. The clinician said any reform in the area needed to recognise the commonality of needs across the range of lung conditions, whatever their cause and diagnosis. This was apparent in the Canberra Lung Life Support Group, where consumers with a range of COPD and non-COPD conditions expressed similar needs for support and access to assistance.

#### Data on COPD in the ACT

Currently, limited data appears to be collected by, or be publicly available from, ACT Health or Canberra Health and Community Services on the COPD population in the ACT. The most recent data on the ACT Health website is for 2015, which shows only that COPD was the sixth leading cause of "disease burden" in the ACT at that time.<sup>47</sup>

The absence of more current and detailed ACT health data on COPD is an impediment to improving health service planning for people with COPD.

Public health publications like the Focus Series do not cover COPD. The Focus on Healthy Aging in the ACT document provides minimal useful information and nothing on COPD.<sup>48</sup> Moreover, the COPD Patient Information Booklet on the Canberra Hospital and Health Service and ACT Health websites is extremely dated (2011)<sup>49</sup> and many of the services which were available then are no longer available.

There are some other data sources, such as the Fourth Australian Atlas of Healthcare Variation, which states that in 2017-18, there were 916 potentially preventable hospitalisations from COPD, with minor variations across Canberra.<sup>50</sup> "Potentially preventable hospitalisations" are a health system performance indicator of accessibility and effectiveness used in relation to both the Commonwealth State/Territory Healthcare Agreements and in Commonwealth agreements with the Primary Health Networks. The data is principally derived from hospital admissions.<sup>51</sup> The term is defined as follows:

A potentially preventable hospitalisation is an admission to hospital for a condition where the hospitalisation could potentially have been prevented through the provision of appropriate individualised preventative health interventions and early disease management, usually delivered in primary care and community-based care settings (including by general practitioners, medical specialists, dentists, nurses and allied health professionals).<sup>52</sup>

While this data showed the ACT had a low rate of such admissions compared to other jurisdictions, the table of rates across years showed a minor increase in the rate of preventable admissions between 2014-15 and 2017-18.

# Chapter 3: Best Practice Care for people with COPD in Australia

### **COPD-X** and **GOLD**

One positive thing for people with COPD is that there are well-established, frequently updated evidence-based guidelines for best practice COPD management available. These arose from collaborative work between the World Health Organization (WHO) and the United States National Heart, Lung and Blood Institute which produced the Global Initiative for Chronic Obstructive Lung Disease (GOLD) Workshop Report in April 2001.

A multidisciplinary Steering Committee was established in May 2001by the Thoracic Society of Australia and New Zealand and the Australian Lung Foundation (now Lung Foundation Australia). The Committee was established in response to the National Health and Medical Research Council call for evidence-based guideline development. It used the GOLD Report and systematic reviews and meta-analyses from the Cochrane database to produce clinical practice guidelines for Australia in a document entitled *the COPD-X Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease* (the COPD-X Plan). The full history of this process is set out in the COPD-X Plan.<sup>53</sup>

The COPD-X Plan is released annually and updated quarterly. It is an extraordinarily useful resource for clinicians, consumers and public policy purposes, that outlines the evidence base across the key areas of COPD best practice care. The following Table from the COPD-X Plan provides the Key Recommendations across the COPD-X areas. These are:

- C: Case finding and confirm Diagnosis;
- O: Optimise function
- P: Prevent deterioration
- D: Develop a plan of care;
- X: Manage eXacerbations.

#### Key Recommendations of the COPD-X Plan Guidelines 2021

C: Case finding and Confirm diagnosis		
	*NHMRC level of evidence	Strength of recommendation*
Smoking is the most important risk factor in COPD development.	1	Strong
A thorough history and examination is the first step in COPD diagnosis.	III-2	Strong
COPD is confirmed by the presence of persistent airflow limitation (post-bronchodilator FEV <sub>1</sub> /FVC <0.7).	III-2	Strong

Diagnosis of COPD should be accompanied by regular assessment of severity.	III-2	Strong
	*NHMRC level of evidence	Strength of recommendation*
If FEV <sub>1</sub> increases >400 mL following bronchodilator, consider asthma, or co-existing asthma and COPD.	III-2	Strong
Further investigations may help a) confirm or exclude other conditions (either co-existing or with similar symptoms to COPD) and b) assess the severity of COPD.	III-2	Strong
Referral to specialist respiratory services may be required.	III-2	Strong

O: Optimise function		
Assessment is the first step to optimising function.	III-2	Strong
Optimise pharmacotherapy using a stepwise approach.	I	Strong
Adherence and inhaler technique need to be checked on a regular basis.	1	Strong
Non-pharmacological strategies (such as pulmonary rehabilitation and regular exercise) should be provided to all patients with COPD.	1	Strong
Comorbid conditions are common in patients with COPD.	111-2	Strong
Palliative care - ideally from a multidisciplinary team which includes the primary care team - should be considered early, and should include symptom control and addressing psychosocial issues.	II	Weak

P: Prevent deterioration		
Smoking cessation is the most important intervention to prevent worsening of COPD.	II	Strong
Preventing exacerbations has a key role in preventing deterioration.	III-2	Strong
Vaccination reduces the risks associated with influenza and pneumococcal infection.	Ι	Strong
Mucolytics may benefit certain patients with COPD.	I	Strong
Long-term oxygen therapy has survival benefits for COPD patients with hypoxaemia.	1	Strong

	*NHMRC level of evidence	Strength of recommendation*
D: Develop a plan of care		
Good chronic disease care anticipates the wide range of needs in patients with COPD.	1	Strong
Clinical support teams working with the primary healthcare team can help enhance quality of life and reduce disability for patients with COPD.	III-2	Weak
Patients may benefit from self-management support.	I	Strong
Patients may benefit from support groups and other community services.	III-2	Weak
X: Manage eXacerbations		
A COPD exacerbation is characterised by a change in the patient's baseline dyspnoea, cough, and/or sputum that is beyond normal day-to-day variations, is acute in onset, and may warrant a change in regular medication or hospital admission.	-2	Strong
Early diagnosis and treatment of exacerbations may prevent hospital admission and delay COPD progression.	111-2	Strong
Multidisciplinary care may assist home management of some patients with an exacerbation.	1	Weak
Inhaled bronchodilators are effective for initial treatment of exacerbations.	I	Strong
Systemic corticosteroids reduce the severity of, and shorten recovery from exacerbations.	1	Strong
Exacerbations with clinical features of infection (increased volume and change in colour of sputum and/or fever) benefit from antibiotic therapy.	1	Strong
Controlled oxygen delivery (0.5-2.0 L/min) is indicated for hypoxaemia in patients with exacerbations.	11	Strong
Non-invasive ventilation (NIV) is effective for patients with rising $P_aCO_2$ levels.	1	Strong
Consider pulmonary rehabilitation at any time, including during the recovery phase following an exacerbation.	1	Strong
Patients with COPD discharged from hospital following an exacerbation should receive comprehensive follow-up led by the primary healthcare team.	1	Strong

\*The GRADE system was used to grade the strength of recommendations. See reference for further information.<sup>54</sup>

## **COPD-X** best practice education materials for

#### health professionals

There is very useful material available for health professionals<sup>55</sup> from a range of sources. All of these are based upon the COPD-X and GOLD work and are intended to make the implementation of the COPD-X Plan guidelines easier, especially for primary care practitioners, including general practitioners, practice nurses, Aboriginal health workers and pharmacists, all of whom have important and emerging roles in the management of the care of people with COPD in the community, rather than hospital. These include:

- The COPD-X Concise Guide, a 40-page guide which was developed to assist primary care providers improve care for people with COPD <u>https://lungfoundation.com.au/resources/copd-x-concise-guide/;</u>
- A GOLD COPD Pocket Guide for Health Professionals in English <u>https://goldcopd.org/wp-content/uploads/2020/03/GOLD-2020-POCKET-GUIDE-ver1.0\_FINAL-WMV.pdf</u> and translated into Spanish, French, German and Mandarin <u>https://goldcopd.org/translated-gold-pocket-guides/;</u>
- A series of tools for primary health professionals including the COPD Action Plan (and a Fact Sheet on How to write a COPD Action Plan), Inhaler Medicine Charts, Inhaler Device Fact Sheets, Exacerbation Algorithm <u>https://lungfoundation.com.au/resources/?user\_category=32</u>, and a specific Primary Care Respiratory Toolkit <u>https://lungfoundation.com.au/primary-care-respiratory-toolkit/;</u>
- A single sheet summary of the Stepwise Management of stable COPD (including a chart on the back which shows which pharmacological therapies can be used together) <u>https://lungfoundation.com.au/resources/stepwise-management-ofstable-copd/</u> (see below on page 26);
- The National Prescribing Services MedicineWise COPD management advice for health professionals <u>https://www.nps.org.au/professionals/chronic-obstructivepulmonary-disease-copd</u>; and
- On-line education resources on COPD under the auspices of the Primary Healthcare Networks – in the ACT, this is the Capital Health Network, and the information is made available to Southern NSW and ACT through the Community Health Pathways website – topics here include COPD, COPD Assessment, Spirometry Testing and Interpretation, Stable COPD Management and Review, Medications in COPD, Acute Exacerbation of COPD, Late-Stage / Palliative COPD. Specific diagnostic and relief/referral education material is also available, such as Home Oxygen, Home Oxygen Suppliers in Southern NSW, Pulmonary Function Testing Referrals, Pulmonary Rehabilitation Referrals, Urgent Respiratory Referrals, Non-urgent Respiratory Referrals, and Respiratory Specialised Advice <a href="https://actsnsw.communityhealthpathways.org/">https://actsnsw.communityhealthpathways.org/</a>.

Figure 1: Lung Foundation Australia – Stepwise Management of COPD (1)

## STEPWISE MANAGEMENT OF STABLE COPD



Source: https://lungfoundation.com.au/resources/stepwise-management-of-stable-copd/

#### Figure 2: Lung Foundation Australia – Stepwise Management of COPD (2)



Source: https://lungfoundation.com.au/resources/stepwise-management-of-stable-copd/

# Education materials providing consumer information on COPD best practice

In addition to Internet access to many of the above resources for practitioners, there are also a wide range of evidence-based resources specifically for consumers and carers, based upon the Global Initiative for Chronic Obstructive Lung Disease (GOLD) work and COPD-X.<sup>56</sup> Most of these materials appear to only be available in English, with some using simplified English with pictures. A selection includes:

- A plain English version of information for consumers from GOLD What You Can Do about a Lung Disease called COPD <u>https://goldcopd.org/wpcontent/uploads/2019/02/GOLD-Patient-Guide-2019.pdf</u>.
- A wide range of videos and publications from Lung Foundation Australia, covering the basics and more detailed support and information as well as a respiratory nurse phone in service <u>https://lungfoundation.com.au/consumers-carers/living-with-a-lung-disease/copd/overview/</u>.
- National Prescribing Service (NPS) MedicineWise Chronic obstructive pulmonary disease (COPD) explained for consumers <u>https://www.nps.org.au/consumers/chronic-obstructive-pulmonary-diseasecopd-explained,</u>
- COPD-X publications including the full COPD Plan guidelines can also be helpful for consumer and carers – <u>https://copdx.org.au/</u>. All updates are automatically sent to the person, if they sign up for them.

There are some tools that consumers and providers can use together particularly in relation to care planning and knowing what self-management involves. For example, *My COPD Checklist* (on page 29) provides a single page guide on self-management for consumers and acts as a discussion list for primary care providers to provide useful information to consumer or carer questions. Similarly, the *My COPD Action Plan* (on page 64) documents what a consumer can do to prevent hospitalisation, to know when they really need to go to hospital, or when there are other options. This tool is designed to be completed jointly by the consumer and the provider as part of an agreed care strategy, which is discussed below in Chapter 7.

#### Figure 3: Lung Foundation Australia – My COPD Checklist

# My COPD Checklist

This checklist is designed to help you self-manage your COPD. If you are unable to answer **YES**  $\checkmark$  to all of these questions, make an appointment with your doctor or other health professional to discuss the issue further.

My diagnosis of COPD has been confirmed by spirometry	Spirometry is a simple breathing test used to confirm a diagnosis of COPD. Your doctor will read the results to tell if you have COPD or another lung condition such as asthma. It is important to have an accurate diagnosis so you can start the right treatment.
l understand when and how to use my COPD Action Plan	A flare-up (exacerbation) is when your symptoms worsen. It is important that you can identify a flare-up early so you can start treatment. A COPD Action Plan provides instructions on what to do if you have symptoms of a flare-up.
l understand my medicines	There are a number of different medicines that can help improve your breathing. Some medicines help open or widen your airways. Others relax the muscles around your airways making breathing easier. Taking your medicines as prescribed by your doctor will help you control your COPD symptoms. Speak to your doctor if you have questions about your medicines.
I can use my inhaler device correctly	Using an inhaler device is a skill. A trained health professional should show you how to use each inhaler and assist you to practice to get the technique right.
My vaccinations are up-to-date	Having vaccinations for influenza and pneumococcal pneumonia can reduce the risk of a flare-up (exacerbation) of symptoms, particularly during the winter months.
I have completed pulmonary rehabilitation	Pulmonary rehabilitation is an exercise and education program provided by specially trained health professionals. It teaches you how to exercise safely and how to manage your breathlessness. Research shows that pulmonary rehabilitation reduces frequency of COPD flare-ups and can prevent hospital admissions.
l exercise regularly	After you finish pulmonary rehabilitation it is important to continue exercising. This will help maintain your physical and respiratory fitness. Lung Foundation Australia's Lungs in Action program is a safe and fun community-based exercise class. Call Lung Foundation Australia on 1800 654 301 to find your closest Lungs in Action class.
If I smoke, I have been offered support to quit	Quitting smoking will dramatically help your health. Many people need help to quit smoking. Speak to your doctor about treatment options like nicotine replacement therapy (NRT), other oral medications and support such as coaching or counselling.
I have regular visits with my health care team	Living well with COPD is based on a partnership between you and your health care team. Your COPD may change over time. It is important to monitor your symptoms and discuss any change with your health care team.
I have been provided with information about COPD	There are steps you can take to control your symptoms and slow the progression of COPD. Call Lung Foundation Australia on 1800 654 301 to access COPD information and resources

Source: https://lungfoundation.com.au/resources/my-copd-checklist/

# Chapter 4: Overview of current arrangements in the ACT for people with COPD

### **General Practice, the Primary Health Network and other Primary Care**

General practices provide the backbone of day-to-day care for people with COPD. This is supplemented by specialist care in the community, either through private specialist consultations or respiratory clinics. Primary diagnosis of COPD can be done by general practitioners, practice and community nurses, Aboriginal Health Workers and others using clinical diagnosis and spirometry. This is covered under Medicare. This is an emerging role for Primary Care and the Primary Health Network is playing an important role in ensuring that Primary Health providers are skilled in this area. It is hoped that this will allow earlier diagnosis, given that for many years the most likely diagnosis of COPD was the person's first admission to hospital with a serious illness attributable to COPD.<sup>57</sup>

More details on the role of primary health care in COPD diagnosis and management are included in Chapter 7 in the section on Case finding and Confirm diagnosis, including the role of pharmacies.

#### **Chronic Disease Management in the ACT**

COPD comes under the broad context of Chronic Diseases in ACT Health and Canberra Hospital and Health Services. There have been problems in chronic disease management over the past decade, which resulted in a strongly critical report from the ACT Auditor-General in 2020.<sup>58</sup> Overall, they showed a failure of governance and service provision in the field of chronic disease management, despite a series of frameworks, strategies and Commonwealth State Agreements. Planned projects did not occur and existing programs were terminated without clearly documented reasons and often without evaluations of their effectiveness. COPD was one of the areas covered by the Chronic Disease Management Program.

The content of the Auditor General's report is consistent with the perceptions of consumers, some of whom were diagnosed more than 20 years ago and have lived with their condition through the period covered by the Audit. Independent to the findings of the Auditor, consumers had mentioned that some services had declined or disappeared. This accelerated with the commencement of COVID-19 in early 2020, as face-to-face services (such as exercise classes) ceased operating.

### **Inpatient Respiratory Services and COPD**

When people with COPD have an acute exacerbation of their condition, they currently often end up in hospital. Until recent developments in spirometry allowed early diagnosis in primary care, hospital inpatient services were where people were often first diagnosed with COPD, on their first or second admission with a respiratory issue.

People with COPD in Canberra or surrounding NSW can be admitted to The Canberra Hospital (TCH), where there is a staff of 7 full-time and part-time Respiratory Physicians and a COPD Nurse in the Department of Respiratory and

Sleep Medicine. They are can also be admitted to Calvary Hospital, where there are some Respiratory Specialists.

### **Outpatient Respiratory Clinic Services**

Outpatient specialist respiratory services of various kinds operate through the Respiratory Clinic at TCH, which runs 5 days a week through the Department of Respiratory and Sleep Medicine. Lung Function Testing services are also available through the Respiratory Clinic. Referrals to both must be made through the patient's general practitioner. Lung Function Testing is readily available, with very short waiting times. There are no Outpatient Respiratory Clinic Services at Calvary Public Hospital. There are apparently few referrals to TCH Respiratory Clinic from people who are treated in Calvary Public Hospital. Calvary Specialist Outpatient Clinic includes some respiratory services, but no other information about these services has been able to be obtained, except that there is no COPD nurse at Calvary.

While there is no public information available on delays accessing bulk-billed specialist care through the Outpatients Respiratory Clinics, consumers mentioned waiting times of 2 years to see a specialist. Discussions with the Respiratory Clinic staff noted that consumers were triaged into three categories, and the timeframe for an appointment depended upon the category they were placed into. Given the long term nature of COPD and its relative stability in the absence of an exacerbation, this often meant that people with COPD were placed into the lowest urgency, Category 3, and Outpatients Clinic staff confirmed that this could mean a wait of 2 years.

An important consequence of this delay in being able to access bulk-billed specialist services, is that ACT consumers are unable to access Pulmonary Rehabilitation services until they have seen a specialist, either as an inpatient or an outpatient, and are referred to these services. It was noted that consumers in NSW were able to access Pulmonary Rehabilitation through a general practice referral, which meant people were able to access the services required much sooner.

#### **Domestic Oxygen and Respiratory Support Scheme**

The Domestic Oxygen and Respiratory Support Scheme (DORSS) is an ACT Community Health service which provides home-based oxygen supplies for people who have a clinical need for supplemental oxygen when not in hospital. Eligibility Criteria are set out in a Canberra Hospital and Health Services Clinical Procedure as follows:

To be eligible for the ACT DORSS individuals must:

- Be a permanent resident of the ACT
- Be living in the community (excluding high level care nursing homes)
- Be an Australian citizen or the holder of a permanent visa
- Have not received compensation through insurance or legal recourse or damages in respect of the disability for which the item has been prescribed. However in exceptional circumstances where an applicant has received a compensation payment, some years have elapsed and the applicant can demonstrate hardship, discretion may be used to provide assistance under the ACT DORSS

- Be ineligible to receive the equipment requested from any other funding program
- Not be an outpatient who is provided with long-term equipment by their treating hospital for an acute medical condition
- Not be able to make an equivalent claim for the required appliance through their Private Health Fund
- Meet the medical eligibility criteria for the supply of oxygen and related respiratory supplies as stated in References in this document in line with the Thoracic Society of Australia and New Zealand (TSANZ) guidelines (<u>Adult</u> <u>Domiciliary Oxygen Therapy</u>)
- Be referred by an approved consultant or approved advanced trainee using the Referral to the ACT Domiciliary Oxygen Support Scheme form 25505 (0212) found on the clinical forms register.

Generally, consumers felt that obtaining access to the program was reasonable and there is no waiting time once the supply is requested. However, there were concerns about the lack of availability of portable oxygen concentrators under this program to better facilitate people moving around the community. The Canberra Lung Life Support Group researched this and made recommendations to Government, but these were not acted upon. Similarly, oxygen tanks are only provided free to a basic level, which does not provide enough oxygen when someone is moving around outside in the community. Consumers said that this often meant that people who were active in the community were limited in their participation through the significant costs of additional oxygen cylinders.

Consumables, such as masks, nasal prongs and tubing were seen as another significant expense. There is assistance for these costs under some specific programs, but these are not available to everyone. In addition, for safety reasons, there have been problems with obtaining oxygen supplies for people where there are other people in their household who smoke.

#### **Pulmonary Rehabilitation Service**

Face-to-face Pulmonary Rehabilitation Services are available through Canberra Health Services (CHHS) and are provided under an Operational Guideline CHHS 18/039.<sup>59</sup> Consistent with COPD-X Plan, the CHHS Operational Guideline states that:

Pulmonary Rehabilitation is a comprehensive intervention based on a thorough patient assessment followed by patient tailored therapies that include, but are not limited to, exercise training, education, and behaviour change, designed to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long term adherence to health-enhancing behaviours.

The CHHS program provides a comprehensive individualised assessment, followed by an 8-week group program of 2 sessions a week. The exercise program requires completion of an individualised exercise program for one hour twice a week, with an additional weekly information session on self-management issues conducted by one of the multidisciplinary team members. Referrals into the program are limited to respiratory physicians, or, when the person is in hospital, from the CHHS physiotherapists and the COPD Clinical Nurse Consultant.

Referrals are not accepted from General Practitioners or community physiotherapists and a patient who is not an inpatient must have a referral from a respiratory physician to be allowed to participate. A person referred by a respiratory physician does not need to have been hospitalised. Referrals are triaged by a senior physiotherapist using a three-tier categorisation. A patient is classified as Category 1 if the assessment or program will prevent them being hospitalised or prevent rapid deterioration in their health status. Category 2 patients are those who are pre or post lung transplant, post hospitalisation for acute respiratory exacerbation, new respiratory diagnosis or severe disease with specialised needs. Category 3 is any other referral than those already listed. There are also specific eligibility criteria and exclusions, mainly to do with other health conditions that may make participation difficult or pose a health risk.

#### **Other exercise services**

There are currently two other services that provide physical activity assessment and/or services for respiratory health. First, there is a supervised student-led Exercise Physiology Clinic run through the University of Canberra. A person needs a referral from their GP to attend. People have an individualised exercise prescription developed for \$40 by a student under the supervision of fully qualified and accredited clinicians. An assessment can be done face-to-face or via Telehealth if preferred. The service states that:

The most up to date evidence-based research is used to identify participants physical strengths and limitations and used to develop individualised safe and prescriptive exercise programs.

There is also a regular Lungs in Action exercise class which consumers can attend for up to 20 weeks per year for a small fee.<sup>60</sup>

This class focuses on maintaining or improving lung health and pulmonary function. Participants' blood pressure and oxygen levels are monitored before, during and after exercise to ensure exercise intensity and recovery is appropriate. The class finishes with a group breathing and relaxation session.

Once people have finished either the pulmonary rehabilitation service or the Lungs in Action sessions, there is another service which runs from the Canberra Institute of Technology in Bruce. Lungs in Action classes are conducted at the CIT Fit & Well Centre,<sup>61</sup> and have only just recommenced in May 2021 post COVID-19. They are described as follows:

Lungs in Action is Australia's community-based maintenance exercise program for people with stable chronic lung conditions who have completed pulmonary rehabilitation. It is also suitable for people with stable ... class II & III heart failure who have completed heart failure rehabilitation. Lungs in Action classes are suitable for people using supplemental oxygen and/or walking frames. Seated options available if required. The Lungs in Action classes are based on the model of Lung Foundation Australia, details of which can be found at <a href="https://lungfoundation.com.au/patients-carers/support-services/lung-disease-and-exercise/lungs-in-action/">https://lungfoundation.com.au/patients-carers/support-services/lung-disease-and-exercise/lungs-in-action/</a>. The website of Lung Foundation Australia also includes written and video resources to assist people with COPD and other lung conditions to keep physically active safely. The Maintaining Movement series of 18 videos is one of these.<sup>62</sup> There are many other resources as well at <a href="https://lungfoundation.com.au/patients-carers/support-services/lung-disease-and-exercise/">https://lungfoundation.com.au/patients-carers/support-services/lung-disease-and-exercise/</a>.

There are also community classes suitable for people with COPD in Chifley at the Chifley Health and Wellness Centre. These classes are run by the YMCA <a href="https://ymcacanberra.org.au/fitness-health-recreation/chifley-health-and-wellness-centre/">https://ymcacanberra.org.au/fitness-health-recreation/chifley-health-and-wellness-centre/</a>. There is an exercise physiologist there to help design individualised program, depending upon a person's goals and exercise capacity.

Community exercise classes, including Sit and Be Fit, tai chi, yoga and a range of more active social activities like Zumba and Line Dancing, are available for quite low cost through places like the Tuggeranong 55 Plus Club <a href="https://55plusclub.org.au/activities/exercise/">https://55plusclub.org.au/activities/exercise/</a>. Woden Seniors offers two levels of formal exercise classes and other physical activities, like various kinds of dancing, tai chi, carpet bowls and Table Tennis <a href="https://www.wodenseniors.org.au/what-we-offer/details/">https://www.wodenseniors.org.au/what-we-offer/details/</a>. Other seniors centres throughout Canberra offer similar activities, for example, Canberra Seniors based in Turner

https://canberraseniors.org.au/here/activities/ and Belconnen Seniors https://www.belconnenseniors.com.au/internal</u>. Lists of Seniors' groups and activities and places to help with keeping active are available through Council on the Ageing (COTA) ACT at the Hughes Community Centre.<sup>63</sup> Information can be obtained via their website <u>https://www.cotaact.org.au/information/resources/brochures/</u> or from their office in Hughes. There is also a Seniors Information Service on 02 6282 3777.

### Canberra Lung Life Support Group and Lung Foundation Australia

The Canberra Lung Life Support Group is one of the key consumer and carer support groups for people with COPD and other lung conditions in the ACT. It describes its role as:

The Canberra Lung Life Support Group is the local support group for people with a variety of chronic lung conditions and their carers. The group offers support to each other, including information about navigating the health system - the doctors, the treatment, the medicines, the oxygen, as well as the assistance they can get. The group is part of the national body, Lung Foundation Australia.<sup>64</sup>

The Group's members have provided significant assistance with this project, and I am personally very grateful for the time they have spent working with me - describing their experiences and suggesting ways things could be done better. Some members of the ACT Sleep Apnoea Group who have COPD also participated in the research for this report.<sup>65</sup>

Lung Foundation Australia provides other peer support options including virtual support groups, telephone support groups and one-on-one telephone support, all of

which can be accessed through <u>https://lungfoundation.com.au/patients-carers/support-services/peer-support/</u>.

Lung Foundation Australia also provides support through their Respiratory Care Nurse phone service, which is based in Brisbane but can provide advice to consumers throughout Australia for people living with COPD or bronchiectasis. A phone appointment needs to be made, either by calling Freecall 1800 654 301 or booking on-line <u>https://lungfoundation.com.au/patients-carers/support-</u> <u>services/support/.</u> The Respiratory Care Nurse can also assist a patient to complete a COPD care plan, which can then be used by the patient to talk with other members of their care team.

Lung Foundation Australia also runs educational webinars for consumers and carers on many lung-related issues <u>https://lungfoundation.com.au/patients-carers/support-</u><u>services/webinars/</u> and also provides connections to other services that may be required through the course of a long term lung condition, such as COPD.

# Chapter 5: Consumer and provider identified service gaps

This chapter outlines who we consulted with for the project and how the consultations were run. It then highlights the concerns raised by consumers, providers and the consumer focus group. Some of the concerns of consumers and providers have been described in Chapter 4: *Overview of current arrangements in the ACT for people with COPD* and some will be discussed in Chapter 6: *Enacting COPD Best Practice in the ACT*.

#### The project plan and implementation

This project aimed to:

- describe the current system for treating people with COPD in the ACT,
- look at current best practice, and
- speak with those who had COPD about their experiences.

A project information sheet, interview outline and consent documents were prepared and approved by HCCA. C copies of these are included at Attachment A to this Report. 34 individuals and organisations were contacted and invited to participate in the research. Some organisations contacted their members and I spoke at a meeting of the Canberra Lung Life Support Group. Seven individual consumers responded – two via video conference, three through a small focus group and two via telephone. Some health professionals and administrators were very generous with their time, as were organisations like the Primary Health Network. Input was received from the Canberra Hospital specialists and respiratory and Chronic Disease staff, Calvary Public Hospital, general practitioners and service providers in the community. 10 additional participants were contacted through other participants.

Some groups are particularly impacted by COPD in the Australian community, including Aboriginal and Torres Strait Islander people and people from lower socioeconomic circumstances.<sup>66</sup> Our research included input from one Aboriginal and Torres Strait Islander person, who also provided information on the COPD experience of relatives and family members. We also contacted one of the NSW Primary Health Networks (Grand Pacific Health) which works with Aboriginal and Torres Strait Islander people living in NSW within the area serviced by the Canberra Hospital and with Winnunga Nimmityjah. Unfortunately, they were not able to assistance at that time. It is important that further policy work is done in partnership with Aboriginal and Torres Strait Islander people and organisations to ensure their voices and experiences shape improvements to COPD care and support to help reduce the disproportionate rate of COPD experienced by them.

Similarly, a better understanding of the lived experiences of people with COPD from low socio-economic backgrounds is needed. Some of the concerns raised in this research by people affected by poverty arose from their limited financial resources. For example, they could not afford additional oxygen if the limited supplies available under the DORSS system was not sufficient. They were also unable to "choose to go private" when there were long waits for access to public services and less able to afford costs such as exercise classes and transport. If they had several co-existing
conditions, the cost of multiple medications was prohibitive. Limited access to computers, phones and information could also be problematic. Some of these financial challenges were also reported by people who were not living in poverty.

People affected by poverty share the access issues faced by all consumers. The lack of generally available information on self-management and wellbeing raised by most consumers is then likely to be compounded by a lack of financial resources. The *Fourth Australian Atlas of Health Care Variation* identified both these groups as over-represented in the national data on people with COPD as did the AIHW's most recent COPD Report discussed in Chapter 2Identifying the specific impacts of policies and practices on consumers affected by poverty will ensure that any solutions address their needs. Active engagement of this vulnerable group of the population will be an important part of reform efforts.

Genuine consumer engagement is particularly important as the health system moves to operationalise a consumer centred system. Much health care is still structured around a biomedical model of treatment and care. While medical treatment and monitoring is important for long term conditions like COPD, helping people to live their fullest lives with their underlying health conditions is beyond the bounds of health care.

A comprehensive approach to living well with COPD will help someone to learn to live the life they want with limiting effects of the medical condition. These effects can come with different speeds over time. People need knowledge, confidence and financial resources to meet the extra costs of their condition. They may need flexible strategies to help maintain their wellbeing and accessible ways to seek advice. They may need someone who they can ask personal questions that they may not be comfortable asking in some medical encounters, such as ways to accommodate their sexuality within their condition. Needing to know what they **could** do was a strong message from people interviewed.

# **Overview from the interviews and research**

Due to the short time frame of the project and the difficulty accessing some of the groups, the direct input from consumers, carers and health professionals was supplemented by academic and unpublished literature and material provided by consumers and carers. One interesting result was that there was a common view about the system that existed and a general sense of good will towards improving it. Views about the problems were fairly consistent.

Finding out about the system was much more complex than expected. Current arrangements do not operate in a coordinated, holistic way based on the needs of those with COPD. There is detailed knowledge of what is best practice in relation to COPD, but care does not appear to be planned or structured in a way which will lead to the best outcomes for consumers over their potentially long journey with the condition in a manner consistent with the knowledge. This lack of explicit plans for early diagnosis and coordinated and integrated care, and the minimal support and assistance for consumers and their carers to learn the skills of self-management, are preventing the ACT Health system from delivering best care in terms of patient outcomes and efficiency.

Up-to-date data on the COPD-affected population in the ACT is not readily available. While the *Fourth Australian Atlas of Healthcare Variation* states that there were 916 potentially preventable hospitalisations for COPD preventable admissions in the ACT in 2017-18,<sup>67</sup> little analysis appears to be being done within the health system about how to address this issue. The Atlas further states that:

The high rate of hospitalisations for COPD reported in this Chapter is unacceptable, and we must implement the strategies we know can improve the health of people with this condition.<sup>68</sup>

Many of these strategies to improve outcomes for people with COPD are covered in *Chapter 7: Enacting COPD Best Practice in the ACT*, where the recommendations of the COPD-X Plan are discussed in detail. What is missing are pathways to implement those known strategies locally in our community. For example, many people are unaware they have COPD until their condition is quite advanced. However, there does not currently seem to be a plan for achieving early diagnosis. Other system barriers include gateway issues for time critical services with known benefits to consumers, that result in treatment delays when people are unable to access services because of delays in the gateway provider. An example of this is the long delay to access public rehabilitation specialists through the outpatient clinics to get a specialist referral necessary for access to pulmonary rehabilitation services. The ACT currently has a fractured and inadequate system for helping consumers to better self-manage their condition and have the best quality of life they can while living with the condition.

The capacity of people to live better lives with COPD is reduced by the medical lens applied to the condition rather than also looking at social solutions to the disabilityrelated needs of people living in the community. An example of this is the limited availability of oxygen and oxygen devices to allow people to live more actively in the community, without incurring high additional costs for supplementary oxygen and related supplies.

While information materials, including plans and videos for exercising at home, are available on the web through bodies like Lung Foundation Australia, there are limited ways for people without computer access or skills to access this information. Alternative ways to help people to access information or to gain computer skills have not been explored or implemented.

Primary care service models are developing with improved funding for practice nurses, spirometry testing and telehealth services, but these are not yet meshed into other community supports or specialist care services. While there are national goals to address the needs of people with COPD and those who have co-existing chronic conditions including COPD, the paths forward at a local level to achieve these laudable goals are far from clear.

# Problems accessing advice and assistance in a timely menner

# timely manner

Consumers also noted that while in theory most of their symptoms could be managed out of hospital, when there was an exacerbation they needed to be able to access either telehealth advice or community-based health care. Consumers noted that it was difficult to get in to see their general practitioner or specialist on short notice or after hours. They could not access Walk-in Centres because of the chronic nature of their condition. There was no "hospital in the home" arrangement to avoid hospitalisation or to allow people to go home as soon as possible. The only homebased free advice services were through the Lung Foundation Australia Respiratory Care Nurse in Queensland, which is only available Monday to Friday 8am-4.30pm and not on public holidays.

With the recent introduction of Medical Benefits Schedule (MBS) Telehealth arrangements in some medical practices during the first stages of the COVID-19 pandemic in March 2020, and recently extended to the end of 2021<sup>69</sup>, phone or video-based assistance may be more available. Telehealth was originally intended to provide people with essential Medicare funded health services in their homes and reduce their risk of exposure to COVID-19 within the community".<sup>70</sup>

Often the only emergency assistance people with COPD could get if they became ill or worried about their situation after hours, was through the ACT Ambulance Service. Several consumers noted that the Ambulance officers were very helpful and were able to reassure them and relieve some of their symptoms sufficiently (consistent with their COPD Action plan where they had one) so that they did not have to go to hospital. Given the importance of avoiding admissions where clinically appropriate, this "work around" was seen as something desirable by consumers, in the absence of other options.

The COPD-X Plan guidelines indicate that oxygen administration in emergencies needs to be done at as low a level as possible, in case the person with COPD has high levels of carbon dioxide in their blood (hypercapnia when non-invasive air ventilation through a mask may be more appropriate. Hypercapnia indicates the need for hospitalisation. If using the Ambulance service as both as first responders and as a filter to prevent inappropriate hospitalisation is to become part of the "backup" system for consumers after hours, it is important that Ambulance officers be trained to be alert to the symptoms of carbon dioxide retention so they can provide the best emergency treatment for COPD patients.<sup>71</sup>

# **Difficulties accessing specialist advice**

General Practitioners (GPs) interviewed for this project expressed frustration at being unable to easily get prompt specialised advice when they need it for a patient to continue their management in primary care, particularly if the patient was not able to pay for private medical specialist services. One specialist described his experiences in overseas hospitals, where there was a "GP email line", where if a doctor saw a patient and wanted some advice, the GP could email the GP line, and they undertook to return the email on the same day if it was received before 12 midday and the next day if it was after 12 midday. This often meant that the patient was able to be treated in an integrated manner quickly and through a team care approach.

# Services that have disappeared or are irregular

The experiences of consumers and providers of gaps in services seem to corroborate the issues raised in the ACT Auditor-General's 2020 report *Management of Care for People Living with Serious and Continuing Illness*.<sup>72</sup>. Initiatives to address gaps in the system have been trialled in recent years. Unfortunately, many of them appear to have lapsed, including telephone help lines for people with chronic conditions. Some support mechanisms exist, like exercise classes, but are only just

resuming after COVID-19. Services listed in the COPD-X Plan as vital to assist people maintain their health, such as smoking cessation programs, are in short supply. Pulmonary rehabilitation services are rationed in the ACT through gateway barriers, which don't exist in NSW. Communication about new developments and "refresher courses" for people with COPD is limited and not integrated into a single system. Identifying the current availability of services for this report was a challenge and it was clear from conversations with consumers and providers that it was difficult to see a clear service pathway for someone with COPD.

# **COPD** Care or Action plans

While clinical care was often reviewed by GPs and specialists annually or sometimes each 6 months, many people with COPD did not have a formal COPD Plan. Where people had two or more co-existing chronic conditions, there was rarely someone ensuring that the entire care team knew what was proposed in other clinical areas, and that the needs and the desires of the person were being paid due regard. Several people talked of the immense changes that occurred when their carer left or their spouse died, or when they began to experience other changes associated with ageing. There seemed to be no specific way that these changes of life circumstances triggered a review of the person's needs.

# **Funding complexity and changing needs**

Funding complexities with Aged Care packages and the National Disability Insurance Scheme, were reported as creating added complexity. This was easier if there was someone with them to advocate for their needs. Timely advice was a problem in a number of areas. For example, some people who were diagnosed more than 20 years ago had only been given pulmonary rehabilitation assistance once, at the beginning of their journey. They had been told that you could only attend rehabilitation once. Most were curious about whether what they were told to do at 55 was still appropriate as they approached 80. Many of them did not have access to computers and printers and some had poor eyesight or macular degeneration as a co-morbidity. This meant they could not access many of the excellent resources available from COPD-X and from Lung Foundation Australia. They often had no way of learning what peer support resources were available, or even that they existed.

# **Perceptions of Stigma**

Stigma, both in the community and sometimes from health professionals, have been identified by consumers as a concern since development of the COPD-X guidelines were initiated in 2003. In 2006 it was noted that:

Despite the significant morbidity and mortality associated with... (COPD), the disease generally attracts less attention from the community and government than other chronic conditions such as heart disease and cancer. This is because unfortunately COPD is often considered incurable, self-inflicted and relatively resistant to treatment.<sup>73</sup>

These historical views and present misconceptions have also often continued to shape the perceptions and expectations of consumers, the community and general practitioners in relation to COPD.

The image of COPD has a common, though misguided, perception of being a self-inflicted disease of elderly smokers. Compounding this

poor image, sufferers often consider symptoms of the disease to be a natural part of aging and are reluctant to seek medical advice. Primary-care physicians may commonly express a nihilistic view and approach regarding the treatment and prognosis of these patients.<sup>74</sup>

These comments are 15-20 years old. The message that the life course of people with COPD can be positively influenced has been hard to get across. Good pharmaceutical assistance, appropriate physical activity and self-management skills can provide consumers with a longer and higher quality of life after diagnosis with COPD. There has been evidence for more than a decade that there are cost-effective options to achieving this.<sup>75</sup> Often the outdated stigmatising ideas about COPD can act as barriers to good care and delay people getting access to information and medications which can positively influence their life course.

The change in prospects post-diagnosis also appears not to have had a significant influence on the system of care provided to many people with COPD. This transition in understanding starts with early diagnosis. The mindset of all people – consumers, providers and the community - must be changed so that all parties recognise that many people who are diagnosed with COPD are able to live well and actively for the remainder of their life, once they know what to do. People also need to know that sometimes the early symptoms of COPD can appear in people as young as 30 and that they may or may not have been heavy smokers. A 2008 Access Economics report for the Australian Lung Foundation (now Lung Foundation Australia) *Economic Impact of COPD and Cost Effective Solutions* stated:

A more contemporary understanding of COPD is that the condition is highly prevalent and will be an increasing cause of morbidity and mortality worldwide. COPD is now viewed as preventable and treatable. COPD is not solely a pulmonary disease but one with important measurable systemic consequences (it is often reported along with other diseases as a complicating factor). COPD patients need to be comprehensively evaluated to allow an individualised program to be prepared using the latest intervention strategies.<sup>76</sup>

Stigma around cessation or non-cessation of smoking was identified as another challenge for people with COPD, particularly for Aboriginal and Torres Strait Islander people. Many people have difficulty stopping smoking, even where they understood the potential for accelerating their COPD. The attitudes of health providers who implied that this showed weakness or ignorance were felt to be condescending and patronising, and some Aboriginal and Torres Strait Islander families felt that the attitudes were racist. An Aboriginal consumer suggested in the research that Aboriginal people should work to develop their own more culturally appropriate smoking using nicotine replacement therapies and normal "quit" methods, an Aboriginal consumer suggested made that other more intensive, culturally appropriate support might be helpful.

Models of integrated person and family centred care are being developed by the ACT Health Directorate and Canberra Hospital and Health Service. These models should build on past experiences in the ACT set out in Appendix A and use existing evidence-based, best practice guidelines to develop services for people with COPD, with or without co-existing conditions. There are other national strategies described in Appendix B which may also assist in reform.

# The Way Forward – collaboration, complexity and quality of life

What appears to be consistent across the evidence is that accurate early diagnosis, self-management and behaviour change such as stopping smoking and increasing physical activity, and avoidance of hospital admissions as much as possible are key elements of any plan for someone with COPD, especially at the early and moderate stages of the condition. From consumers interviewed, it seems that people who are diagnosed with COPD can go on to lead positive lives, that may be long and of good quality for most of the time. Several people interviewed had received their diagnosis 20 or more years ago and were living in the community in their 70s and 80s. It also was clear that some of their needs had changed as life brought different challenges, but that these were not always accommodated by current systems. Sometimes it seemed that their survival appeared to have taken the health care system by surprise, so that their management did not reflect their actual needs or their individual aspirations.

Given the broad acceptance of the COPD-X Plan, we are well placed to use these to work out a better way of providing for people with COPD in our community, in a timely and efficient way. Recent developments such as telehealth, the potential for greater use of community education through consumer and carer support groups, more systematic linkages between primary care and specialist services and use of practice nurses for monitoring of complex care plans all provide new ways forward. Many will allow primary care, hospital and community care services which better meet people's needs within the community, with more targeted use of hospital and specialist in-patient services, which hopefully will be better for consumers, carers, providers and the community.

The detailed analysis in the next chapter will use the areas defined by the COPD-X Plan, listed above at page 22, to frame the discussion of how to achieve a COPD care and support system framed around the overall best practice "wellness goals" for people with COPD. It may be that this can also be used as a guide to help consumers manage other chronic conditions and to assist consumers with more than one chronic condition to receive more holistic integrated care across all their needs as a "whole person".

# Chapter 6: Enacting COPD Best Practice in the ACT

# **Overview**

This Final Report chapter is shaped around the Key Recommendations from the COPD-X Plan's guidelines found at page 22 above, given we have an existing "best-practice" framework already in existence. The research and interviews for this project showed that many parts of the framework are there, but they are like a partly constructed building. There are lots of rooms there – but finding the way between them is not easy and people with COPD often fall through the holes. Providers also may not know where to go – and the architect seems to have gone to the Bahamas in the middle of the construction. There are also key elements like halls and paths that could have linked things together but don't. Some of these may be apparent in the description of current arrangements and the perceptions of consumers and providers already described. Other gaps and missing or mis-shaped pillars will become manifest, when the building is looked at through the lens of COPD-X.

The national work on lung conditions, on chronic conditions and on Indigenous health, as well as the National Health Reform Agreement between the ACT (and all other States and Territories) and the Commonwealth Government set out in Chapter 6 all seek common goals. Firstly, they seek to establish a consumer centred, culturally appropriate, integrated system, focusing on prevention and minimisation of chronic conditions. Secondly, they focus on treatment, care and self-management to minimise symptoms and reduce physical and mental harm from conditions, to maximise quality of life for those with chronic conditions – whether through single conditions or multiple co-existing conditions. Thirdly, they look to start with populations who have traditionally had worse outcomes and where it is believed that significant health improvements can be made reasonably easily. The work of the Productivity Commission into innovations in chronic conditions also shows that this can also increase efficiency and allow the diversion of unnecessary expenditure into better more effective services.

COPD and lung conditions, as well other co-existing conditions, provide an excellent place for the ACT to trial and implement more integrated systems of care that focus on, for example:

- Prevention of COPD and other lung conditions, for example, through reducing even further, current rates of smoking in both the ACT community, and in the Aboriginal and Torres Strait Islander population of the ACT and surrounds;
- Control of the rate of decline of lung function, through earlier identification of COPD and other lung conditions, better patient education on the skills of selfmanagement and better access to pulmonary rehabilitation and expanded exercise programs;
- Systems of care for lung function that are shared between specialists, general practitioners, practice nurses and specialist COPD nurses, community service providers and self-management, in a way which gives consumers more control and confidence and a greater sense of their own efficacy;

- Enabling people to remain active in the community and keep control of their lives for as long as possible, through evidence-based strategies, such as adequate oxygen supplementation and equipment to allow community engagement; and
- Improving the frequency of case plan development, and the use of plans to reduce the incidence of, and hospitalisation for, exacerbations.

The report uses the COPD-X evidence-based guidelines to identify some areas which could be addressed in different ways in the ACT, as well as suggesting that a process be established to bring together and coordinate those services to reduce bottlenecks and to identify and skill up the necessary workforce to deliver the desired outcomes.

# **C: Case finding and Confirm diagnosis**

# Diagnosis

COPD develops slowly over a long period of time, and for much of that time, it is asymptomatic and causes no disability. There is considerable discussion about whether apparently healthy people should be screened (see below), but the balance of evidence concludes that diagnosis is best done as early as possible once symptoms are present.

Even once someone develops some symptoms of COPD, such as breathlessness or a cough, they may not understand the significance and put them down to getting older or lacking fitness, unless they have seen COPD in other friends or family members. It is important that people in the community and health professionals see that COPD is a condition, where early diagnosis and action can positively impact on the course of the condition and extend people's quality of life by many years. Once a person has symptoms, primary care screening programs can be undertaken by general practitioners, pharmacists, practice nurses, Aboriginal health workers, community nurses and other primary health providers in the community to help detect COPD early.

The first step in determining whether or not someone may have COPD is to ask them to fill in a COPD case finding form, at either a general practice or in a pharmacy or another place where primary care may be delivered. There are now standard "case finding" forms available for general practices<sup>77</sup> and pharmacy use,<sup>78</sup> produced by Lung Foundation Australia<sup>79</sup> to help with early detection in symptomatic people and there are other similar validated questionnaires available. Practice-led questionnaires for case finding generally include a patient's age, whether they are currently smoking or have a smoking history, whether they have worked or lived in dusty or polluted situations, whether they were born prematurely or they have a family history of COPD. Symptoms of concern listed in the 2011 Lung Foundation Australia's Position Paper on COPD Screening are:

- Coughing several times most days;
- Cough up phlegm or mucus most days;
- Out of breath more easily than others of a similar age;
- Experience of chest tightness or wheeze; or
- Have frequent chest infections.80

Where someone has one or more symptoms or characteristics listed, is 35 years or older and does not meet any of the contraindications,<sup>81</sup> the next step is to measure their breathing using a COPD screening device. Lung Foundation Australia states that a COPD screening device is sometimes easier for consumers to use than a Spirometer and requires less training to conduct the procedure and interpret the results so can be more readily used to identify consumers where spirometry will be needed to make a formal diagnosis.

These screening devices are small, simple handheld devices, which help rule out consumers that are unlikely to have COPD. They are sometimes used by consumers with asthma to monitor their lung function at home. The website of Lung Foundation Australia states that, while they are not appropriate for diagnosis of COPD:

they are easy-to-use and require basic training in order to conduct the procedure and interpret the results. They are also less physically demanding than spirometry [for consumers] as they do not require individuals to completely empty their lungs of air.<sup>82</sup>

Various types of screening devices available in Australia include the PiKo-6<sup>83</sup> and COPD-6<sup>84</sup> machines. These are inexpensive and on-line training is readily available on their use. If these devices indicate that diagnosis of COPD may be likely, then COPD can be diagnosed using another simple, non-invasive device called a spirometer, which is the "gold standard" for detecting and measuring fixed airway obstruction. The use of a spirometer requires a higher level of training, but it is able to be done in general practice.<sup>85</sup> Medicare allow payment for the administration of spirometry by a trained practice nurse or nurse practitioner as well as a general practitioner, Aboriginal health worker and some other primary health providers. The test is also more difficult for a person suspected of having COPD, as a patient needs to breathe in as deeply as they can and then breathe out quickly to empty their lungs.

# COPD is confirmed by the presence of persistent airflow limitation (Post bronchodilator $FEV_1/FVC < 0.7$ )

FEV<sub>1</sub> is forced expiratory volume in one second and FVC is forced vital capacity of the whole breath until your lungs are empty. COPD-X advises that because such tests "require high levels of patient effort and cooperation, there are important quality criteria that should be met in conducting spirometry". The recommended clinical indications for carrying out spirometry include:

- breathlessness that seems inappropriate;
- chronic (daily for two months) or intermittent, unusual cough;
- frequent or unusual sputum production;
- relapsing acute infective bronchitis; and
- risk factors such as exposure to tobacco smoke, occupational dusts and chemicals, and a strong family history of COPD.<sup>86</sup>

Spirometry is also important as a way of judging the severity of COPD at diagnosis and over time, and in the words of COPDX:

Spirometry is the most reproducible, standardised and objective way of measuring airflow limitation, and  $FEV_1$  is the variable most closely associated with prognosis.

The following table indicates FEV<sub>1</sub> measurement with severity classification and symptoms used in Australia.

#### Figure 4: Classification of severity of chronic obstructive pulmonary disease (COPD)<sup>87</sup>

	MILD	MODERATE	SEVERE
	Few symptoms	Breathless walking on level ground	Breathless on minimal exertion
Typical Symptoms	Breathless on moderate exertion	Increasing limitation of daily activities	Daily activities severely curtailed
	Cough and sputum production	Recurrent chest infections	Exacerbations of increasing frequency and severity
	Little or no effect on daily activities	Exacerbations requiring oral corticosteroids and/or antibiotics	
Typical Lung Function	FEV₁ ≈ 60-80% predicted	FEV₁ ≈ 40-59% predicted	FEV <sub>1</sub> < 40% predicted

FEV<sub>1</sub>=forced expiratory volume in one second Box adapted from Lung Foundation Australia's Stepwise Management of Stable https://lungfoundation.com.au/resources/?search=stepwise COPD available at

# Case Finding – is screening a good idea?

Despite the importance of early diagnosis, most research on using questionnaires, spirometry, or other office-based screening pulmonary function testing concludes they are not recommended for asymptomatic people.<sup>88</sup> In concluding that such screening has no net benefit, the 2016 United States Preventive Services Task Force (USPSTF) stated that it:89

Did not find evidence that screening for COPD in asymptomatic persons improves health related quality of life, morbidity or mortality. The USPSTF determined that early detection of COPD, before the development of symptoms, does not alter the course of the disease or improve patient outcomes.

Research has concluded that educating primary care providers "to use simple tools among high risk populations in primary care is the only feasible way to reduce the percentage of underdiagnosed COPD".<sup>90</sup> Early detection also facilitates earlier interventions to improve the course of the condition, where possible, before it impacts more seriously on people's health and quality of life. For example, if someone is diagnosed with COPD early and is able to get therapeutic assistance to increase their physical activity before breathlessness makes it more painful and difficult, then that person is likely to be able to maintain their ability to do physical activities for longer and have a higher quality of life.<sup>91</sup> There is more research being done to try and determine at which point such case finding should be done to maximise accurate identification where therapeutic assistance might be able to improve the course of the condition.<sup>92</sup>

Research consultations with consumers and clinicians showed that people generally understood the importance of early diagnosis but that there were few clear systems in place to ensure that people were being identified early. Among consumers who had experience with the condition through family members being ill, it might be the

consumer who self identifies and asks the doctor to test them. However, sometimes symptoms of COPD can be put down by consumers or carers to aging or lack of fitness or a range of other things and so they don't seek help. In some systems of health care, where there is greater continuity of care and attendance, such as where consumers may be enrolled in a particular practice, opportunistically approaching consumers with a known risk factor has been claimed to increase earlier diagnosis of COPD. Similarly, where a patient has a regular general practice or practitioner, it may be that the symptoms are noticed by a doctor or practice nurse earlier.

#### Patient usage of primary care practice patterns in the ACT

It seems likely that early detection might be less likely if someone does not attend a regular general practice or see the same doctor over time. Quite often when someone is diagnosed with a long term condition, they seek a general practitioner who they can work with and who knows their situation. However, it may not be the case over their lifetime.

Before developing a chronic condition requiring consistent monitoring, consumers may obtain services from wherever or whoever they can get in to see when a specific need arises. An "incidental" practice like this may not have detailed information on their medical history or patterns of family health conditions in these circumstances. Their service use can also vary with their ability to pay. For example, the ACT GP bulk billing rate remains the lowest in Australia in 2020-21 (69.4% compared to 89.3% as the national average and 91.1% at the highest level in NSW).<sup>93</sup>

In many cases, consumers may also have to wait some time to see their "usual" doctor, if they are busy.<sup>94</sup> Many practices also rely on relatively short consultations<sup>95</sup> and it seems likely that unless the doctor or practice nurse notices symptoms or asks the patient directly about symptoms, they may not readily be able to opportunistically identify people with COPD who have not already been diagnosed. 83% of consultations in the ACT in 2019-20 were billed to Medicare for appointments of less than 20 minutes.<sup>96</sup> This may mean that if a person is coming for a medical consultation on a specific unrelated concern, a busy doctor may not take the time to obtain information about their smoking history, whether they have lived or worked in dusty or other high-risk environments, their family history or other risk factors in their medical history. Consumers often express concern about time pressures in their health care, even where they have a long term condition.<sup>97</sup>

While doctors may have continuing time constraints, changes in delivery of primary care can serve to support a more engaged continuum of care. For example, the use of clinical nurse consultants and practice nurse has dramatically increased in practices following a range of government initiatives in the early 2000s to provide incentives to employ practice nurses. This has seen a dramatic increase in numbers of practice nurses – a survey<sup>98</sup> showed by 2012 that 63% of practices employed a general practice nurse. The number of general practice nurses at that time was around 11,000 and it is estimated that this will increase to around 14,600 by 2025.<sup>99</sup> Practice nurses and pharmacists can play important roles in case finding and diagnosis of COPD, as can other primary care practitioners. The Capital Health Network is very supportive of all these aspects of Primary Care and the possible new roles that can be developed in COPD diagnosis and management. Similarly, increased use and familiarity with using the electronic My Health Record by both

doctors and consumers may assist in achieving some measure of continuity of care, even where people use multiple practices.

#### Early accurate diagnosis in primary care

Currently, people with undiagnosed COPD are often first diagnosed with COPD when they are admitted to hospital<sup>100</sup> with a respiratory illness such as community acquired pneumonia. However, if diagnosis can be made earlier in community health or general practice before someone becomes acutely unwell, this can improve a patient's longer term health by preserving lung function before they need admission to hospital. Lung condition-related admissions, post diagnosis of COPD, are called "exacerbations" (see below). These can reduce a consumer's lung function significantly for a period of time and can contribute to permanent damage. It would therefore be desirable to have earlier detection before someone becomes sick enough to be admitted to hospital. Consumers interviewed often reported being first diagnosed in hospital, sometimes while admitted for another condition. For example, a person who was admitted to hospital following a heart problem was first diagnosed by the cardiac specialist who was treating her.

The role of primary care through general practitioners, practice nurses, Aboriginal Health Workers, community nurses and others in earlier detection is a developing area. Research into early identification suggests that the "best diagnostic yields" came from practice led questionnaires completed by consumers clinically suspected to have COPD, followed by diagnostic assessment,<sup>101</sup> as discussed above.

Some consumers may also be referred to a doctor, through a pharmacy screening program which also uses a COPD screening device.<sup>102</sup> Such services are available at some Canberra pharmacies.<sup>103</sup> The Pharmacy screening program does not diagnose people with COPD but provides the person with a print-out of their results for follow-up with their doctor to determine if diagnostic spirometry is required. This can be a useful gateway to diagnosis for those people who do not regularly attend a specific medical practice or have difficulty affording a medical consultation but have symptoms that may be of concern, as observed by the person and/or the pharmacist.

Correctly identifying people who have early COPD allows them to have earlier access to self-management and medical interventions that will help them maintain their health as long as possible. Equally, misdiagnosis of COPD might lead to someone receiving the wrong treatment or delayed treatment for the actual condition affecting them, so quality of training for those undertaking spirometry is very important. Research shows that there are both under and over diagnosis problems that need to be monitored through proper quality assurance and checking processes.<sup>104</sup>

#### Asthma and co-existing conditions causing symptoms like COPD

In some situations, spirometry is a necessary but not sufficient diagnostic process for a patient. Complexity of diagnosis of COPD can arise from overlapping symptoms with other conditions. Where this is the case, after preliminary testing is done, it will often be necessary to refer someone to a specialist Respiratory Physician or to have a more complex Lung Function Test.

The COPD-X Plan guidelines set out the indications for referral to specialist respiratory outpatient services. These needs can be met through a consumer

attending a specialist physician as a private patient, but this may be difficult for some consumers to afford. Alternatively, they may be referred to the Respiratory Outpatients Clinic at Canberra Hospital or to the Outpatients Clinic at Calvary, but the wait for an appointment as a public patient can be extensive as noted earlier. There are also barriers to entry for other services, like Pulmonary Rehabilitation, which need to be addressed, to meet the goals of care planning, optimisation of function, prevention of deterioration and management of exacerbations.

The current arrangements for referral to the Respiratory Clinic are complicated by having to be admitted and discharged from the clinic. Once someone finally gets into an appointment, they are often reluctant to be discharged from the clinic's care, even though they no longer need specialist assistance. People talked of not wanting to "lose their place" In case they needed specialist help again in the future. There was little flexibility unless the patient became admitted to hospital, which is of course, something to be avoided where possible. On the other side, sometimes general practitioners are not kept in the loop and so cease to be an active partner in the person's care. Overall, expectations about the interface between self-management, GP day-to-day management, specialist care and access to other services are not clear to each of the people involved and communication and teamwork across clinical domains is complicated even more when a person has several co-existing conditions.

#### **Smoking cessation**

Given that COPD-X states that smoking is the most important risk factor in COPD development and in a range of other conditions, helping smokers to stop smoking is a top priority, especially for those already diagnosed with COPD. While it claimed that some people can stop smoking at a first attempt, this is very unusual and recent research estimates that on average people try to quit 30 times before they successfully quit for a year or more.<sup>105</sup>

Stigma has been acknowledged as a tool in public health to achieve behaviour change for many decades, but the recognition of the "downsides" of this stigma has only more recently been studied. The utility and ethics of using stigma, shame or humiliation have been questioned in relation to behaviour change more generally. It is unlikely to be a harm-free approach for people having difficulty stopping smoking.

Cessation is difficult for many smokers for a number of reasons. Nicotine is highly addictive and because it mimics the neurotransmitter acetylcholine, it often has perceived positive (if short term) effects on concentration, memory and cognitive processing through stimulation of the "nicotinic receptors" which occur throughout the brain. The "buzz" which comes from the nicotine flooding the brain's receptors when either cigarette smoke or nicotine containing vapour is inhaled occurs within 10 seconds, but it goes away within an hour or two. This, in turn, creates a stress response in these same receptors that is likely to lead people to seek another dose of nicotine.

The physical addiction also comes from the stimulation of a part of the brain called the "nucleus accumbens". These neurones release dopamine and create feelings of pleasure and relaxation and it is believed they are involved in the formation and continuation of addictions more generally. An additional reason for difficulty in stopping smoking are the habits which often go along with smoking (such as taking a break from work or socialising). Nicotine substitutes, like patches or gum may help people, by providing some of the good feelings and reducing the withdrawal pain. However, where the use of nicotine was "treating" some underlying anxiety or depression, a person is likely to need assistance in finding other ways of dealing with these underlying issues to permanently cease smoking.

Given this complexity, those seeking to help consumers stop smoking may require a mind-shift to be effective in providing assistance. An attitude of "They could stop if they really wanted to" is unlikely to help a consumer to stop smoking. The health professional may need a deeper understanding of nicotine addiction and the reasons why people may continue to smoke, even while understanding its negative impact on their health. Alternatively, they may need to refer the person for specialist help. It was noted that general practitioners were often not well trained in dealing with addictions or aware of how to assist people with long term nicotine addiction to stop smoking.

There are community resources available to support general practitioners, other health professionals, consumers and family members. Quitline can be contacted by phone on 13 78 48 or via the Internet <u>https://www.quitlinent.org.au/</u> and can assist people at the various different points they may be in deciding to stop smoking, eg Thinking of quitting, Ready to quit and Staying quitted. These also offer help for family members or friends who want to assist someone to quit and health professionals who want to assist their consumers.

Properly trained practice nurses and psychologists or counsellors specialising in treating addictions could have an expanded role in a more integrated COPD management system. It might also be possible to initiate addiction interventions when a person is an in-patient. It was noted by some general practitioners that such specialist intensive assistance was not readily available in Canberra to assist people who are finding stopping smoking challenging.

# **O: Optimise function**

#### Introduction

Once a consumer has been formally diagnosed with COPD and their level of current impairment (if any) in activities of daily living ascertained, there is a need to assess what is needed to optimise their physical, mental and social function for as long as possible. The first assessment provides a baseline from which the efficacy of different treatments or interventions can be judged by both the consumer and the health professional. A history of assessments at appropriate periods can provide a valuable tool for the consumer over their life journey. The psychological impacts of such a diagnosis also need to be considered, as this can impact on their approach to other activities.

Strategies to optimise function may include drug treatments, but it may also include helping them to develop other strategies. The optimisation of functions needs to continue throughout their lifetime and needs to take into account any other conditions which might interact with their COPD. A whole person, whole-of-life assessment is needed to ensure that people maintain and, where necessary, build up their social engagement and activities to help maintain their health and wellbeing for as long as possible. Optimisation can also include developing coping strategies, ensuring adequate rest and good food.

Early and prompt access to pulmonary rehabilitation is a crucial step to helping establish activities that can assist with optimising the person's length of healthful living. With consumers living much longer with this and other co-existing chronic conditions, there is a need for such programs to also include advice on heart and vascular health, bone health and psychological health. Continuing access to periodic rehabilitation assessment through a consumer's life course will facilitate the optimisation of their health and wellbeing for as long as possible.

In some situations, a specialised lung function assessment or referral to specialist respiratory services may be needed as well. This can be needed, for example, where someone's diagnosis may not be clear or they may be in need of oxygen therapy.<sup>106</sup>

# Assessment

The COPD-X Plan 2021 states that the primary goal of assessment is to determine what the goals of care are at any stage of the consumer's life and condition course.

THE PRINCIPAL GOALS OF THERAPY are to stop smoking, to optimise function through symptom relief with medications and pulmonary rehabilitation, and to prevent or treat aggravating factors and complications.<sup>107</sup>

Considering and acting on these goals is described as "one of the most complex clinical issues in the management of COPD" and has a number of different facets and aims across the consumer's life and condition course. These are outlined in the Plan as:

- Active therapy: designed to slow the progress of the condition, through prevention of exacerbations, management of symptoms of the condition, managing any co-existing conditions, with the aim of maintaining maximum health for as long as possible;
- Active therapy with treatment limitations: this is a point when a person becomes less capable of doing their activities of daily living, despite best care being received, and can be signalled by the need for long term oxygen therapy;
- *Palliative and supportive care*: when there is functional decline despite optimal therapy and the aim of care becomes comfort and therapeutic preparation for the next crisis; and
- *Terminal care*: when active management is no longer possible and symptom relief during the dying phase is the main medical concern. This phase is characterised medically by profound weakness, being bed-bound, drowsy for extended periods, disinterested in food or fluids, disorientated to time with poor attention span, and difficulty swallowing medications.<sup>108</sup>

It is important to recognise that these are not discrete phases nor are they one-directional. People may move backward and forwards between these phases and the perception of it as a one way journey can be very trying for carers and consumers alike. In consultations, carers often mentioned that they would present at hospital with their loved one very ill and they would be told that the loved one didn't have long to live. In the research a participant described a man who was caring for his wife who had COPD and this scenario had occurred multiple times. At each presentation where these pronouncements of her imminent death were made, the man felt he grieved for her expected death and started the separation process. When she rallied and pulled through, he had to hold the grief and joy together with the stress of continuing to care for her. He described the exhaustion he felt from living through her expected death each time. He said he felt that these pre-warnings of imminent death in a condition like COPD was actually not helpful for him as her carer nor her as the patient.

Such assessments require a close discussion with a consumer and their carer about their wishes and intentions. In all situations, there is a need to recognise that the consumer and carers needs are multi-dimensional and it is important that the person being assessed is recognised as an active participant throughout. Where someone feels disempowered, part of the role of the health professionals is to help the person recognise the powers within themselves to choose to deal with their health conditions actively. Often when given a diagnosis of a chronic condition, people have been educated to see this as an ending, whereas it is really part of a potentially significantly longer life journey over which a person still has some control. The Director of the Stanford University's School of Medicine's Patient Education Research Centre, Professor Kate Lorig and colleagues in their important book *Living a healthy life with chronic conditions* describes the conundrum:

To answer this, let's look at what happens with most chronic health problems. It is true that these illnesses, such as heart disease, diabetes, depression, liver disease, bipolar disorder, emphysema and other breathing issues, or other conditions often cause fatigue. They also can result in decreased physical strength and endurance. In addition, chronic long-term illnesses may cause emotional distress, such as frustration, anger, anxiety, or a sense of helplessness.

So how can you be healthy when these things may be happening to you? Health is soundness of body and mind, and a healthy life is one that seeks that soundness. A healthy way to live with a chronic illness is to seek soundness of body and mind and work to overcome the physical and emotional issues illness causes. The challenge is to learn how to function at your best regardless of the difficulties life presents. The goal is to achieve the things you want to do and to get pleasure from life.<sup>109</sup>

These goals to achieve the things you want to do and get pleasure from life can only be decided by the patient, with or without their family. It is not a medical or health professional decision, though it might affect the treatment that is appropriate at a specific time. For example, it may be that a specific patient is happy to accept a shorter life and reduced quality of life to continue smoking.

Thus the assessment process to optimise a patient's function must be at the core of the care relationship. The goals of the patient may be informed by the clinical goals set out above. However, the clinical measures suggested by the clinical goals must be adapted to be tools to enhance the achievement of the patient's goals.

So far as the physical assessment aspect is concerned, the COPD-X Plan 2021 also sets out the circumstances in which someone may need additional lung function testing<sup>110</sup>. Where a diagnosis of COPD is clear using spirometry with a trained clinician, it may not be necessary to have a full lung function test before embarking

on drug treatment or non-drug interventions. Exercise testing may also be used to determine whether breathlessness comes from a heart or lung condition. It can also be used to monitor progress and to determine whether a person may need oxygen during exercise. A chest X-ray can be used to exclude some alternatives, such as lung cancer, but is not accurate for diagnosis of COPD, and there are various other tests listed in the COPD-X Plan 2021 which may be needed in specific circumstances, including trials of therapy.<sup>111</sup>

#### Drug therapy, inhalers and pharmaceutical assistance

Drugs for the treatment of COPD can include tablets, inhaled drugs and a variety of different options. The Stepwise approach shown at page 29 provides a summary of the different pharmacological options. This area of expertise is beyond the scope of this report, so far as critical analysis is concerned. The key issues from the consultations were the issue of cost and the need to make sure that people knew what to take when, and that they were able to get assistance with using equipment like inhalers etc.

Sometimes consumers get information about their medications from pharmacists, practice nurses, Aboriginal Health Workers, community nurses or their general practitioners, as well as specialist services. The need to check usage and any problems at medical visits seems likely to help people take their medications in the most efficacious manner and avoid unnecessary side effects. There are extensive guidelines in the COPD-X Plan 2021<sup>112</sup> and many adaptations from this to assist clinicians in developing the most appropriate individual drug treatment plan for individuals with COPD. To achieve best practice, their medications need to be done and checked regularly, to ensure the consumer is benefitting from the chosen medications. and to make any necessary adjustments. This is particularly so when a patient sees several medical specialists for co-existing conditions and may have issues with drug interactions.

#### **Pulmonary Rehabilitation**

COPD-X Plan 2021 says that pulmonary rehabilitation programs "involve patient assessment, supervised exercise training, education, behaviour change, nutritional intervention and psychosocial support". Its aim is "to improve the physical and psychological condition of people with chronic respiratory disease and to promote the long term adherence to health enhancing behaviours" with exercise training being at its core.<sup>113</sup> It should be available to people more than once so that people are able to have up-to-date information for their self-management.

As well as being shown to be cost effective, the following benefits are listed in the COPD-X Plan 2021:

- Reduction in breathlessness and fatigue;
- Reduction in anxiety and depression;
- Improvements in health-related quality of life
- Improvement in peripheral muscle function and exercise capacity;
- A sense of improved control over their condition; and
- Reduction in hospitalisations for exacerbations.<sup>114</sup>

Most of the studies have been done on outpatient hospital-based programs, but there is also evidence of benefit from programs delivered to consumers when they are inpatients or in community and in home settings. While studies have covered programs from 4 weeks to 18 months, most Australian programs and which occur in Canberra are of 8 weeks duration, with two sessions a week. In the ACT one of the weekly sessions includes an education session, and both include exercise sessions. The COPD-X Plan guidelines recommend that pulmonary rehabilitation be offered to any patient with COPD or any other long term respiratory condition who is limited by shortness of breath on exertion.<sup>115</sup>

The health impacts appear to be strongly linked to the exercise components of these programs, but it may be that pulmonary rehabilitation programs which include a more holistic approach can help people sustain their motivation to exercise after the end of the program. Lung Foundation Australia provides good information about Pulmonary Rehabilitation Programs and their location.<sup>116</sup>

Lung Foundation Australia also provides training materials for health professionals to design and deliver pulmonary rehabilitation services for people who have lung conditions, through their Pulmonary Rehabilitation Toolkit,<sup>117</sup> which may also help consumers to understand better what Pulmonary Rehabilitation is all about and to increase their own health literacy. The kit includes a guide to getting started, patient assessment and reassessment forms, an exercise training record and patient education material. It notes that:<sup>118</sup>

The education of patients and their families should be a component of a pulmonary rehabilitation program. ... Changing patient beliefs and behaviours so as to enhance their willingness to maintain their exercise program will help maintain quality of life and exercise tolerance as well as reduce symptoms.

For consumers who like to look at videos on the Internet and have access, there are also specific resources on pulmonary rehabilitation that may help. Lung Foundation Australia has a patient view video.<sup>119</sup> There are a range of different videos on You-tube as well. Some are not Australian-based, but the system used in the United Kingdom is similar and may provide further audio-visual information for consumers and their families.<sup>120</sup>

Lessons could also be transferred from programs for other people with chronic conditions. In the ACT, the Obesity Management Service provides an integrated service providing physiotherapy and exercise physiologist assistance, as well as dietetics and psychology services to help people address negative health impacts, which can be related to weight. This service also provides telehealth follow-up so people can ask questions and to help build their motivation to continue their efforts to improve their health. This might be an appropriate model to trial for lung health and heart health more generally.<sup>121</sup>

#### **Keeping active**

Keeping active and moving is important for people for many reasons throughout their lives. While being more active has significant health benefits for everybody, this is especially so for people with chronic conditions, including COPD. Often before someone is diagnosed with COPD, they become less active, because they become breathless. The British Lung Foundation has a useful diagram explaining the "cycle

of inactivity"<sup>122</sup> - it can be seen as a vicious cycle, because it is a negative spiral of cause and effect.





Source: British Lung Foundation. What happens if I'm not active? <u>https://www.blf.org.uk/support-for-you/keep-active/how-will-it-affect-my-breathing</u>

Initially, just becoming more active in your day-to-day life can help, whether it be doing housework or gardening, playing with your children or grandchildren, walking upstairs or moving around outside or in a shopping mall. Walking up the street or around the block, walking to the shop or to the library, getting off the bus a stop early – these are just some of the ways you can become more active.

This is important whether or not you have a diagnosis of COPD or other lung condition or co-existing condition. A person can become more active, before or after a formal pulmonary rehabilitation program. If you are active on most days of the week, then you will gradually increase your strength and breathing and create a "virtuous cycle" (that is one with positives that build on each other). The British Lung Foundation illustrates this cycle also<sup>123</sup>:



### Figure 6: British Lung Foundation Positive Cycle of Activity

Source: British Lung Foundation. How can being active help my breathing? https://www.blf.org.uk/support-for-you/keep-active/how-will-it-affect-my-breathing

The COPD-X Plan says that people with COPD can aim for the same levels of activity that are healthful for all adults in the community. These are listed in the COPDX-Plan 2021 as:

- Doing any physical activity is better than doing none;
- Be active on most, preferably all, days every week;
- Accumulate 150 to 300 minutes of moderate intensity physical activity or 75 to 150 minutes of vigorous intensity physical activity, or an equivalent combination of both moderate and vigorous activities, each week;
- Do muscle strengthening activities on at least 2 days each week.

The moderate intensity total works out between 30-50 mins 6 days a week of moderate intensity activity and 15-30 minutes of vigorous activity 5 days a week. These levels of physical activity can be challenging for people with COPD and others, particularly if they have been sedentary in their daily lives, for example, sitting down at work, reading, or seated watching television.<sup>124</sup> However, any physical activity is better than none, so this means starting with small amounts of activity, built into daily living and, if possible, doing something you enjoy, can all help. Evidence shows that even a level of less than half that set out above can reduce COPD

mortality significantly, especially where this involved walking or structured exercise.<sup>125</sup>

Formal exercise training can also be important in maintaining health when you have COPD, especially to support the gains made in a pulmonary rehabilitation program. It may require additional rest periods but breathlessness from exercise is generally not harmful. Lung Foundation Australia ensures that the trainers who give their Lungs in Action Exercise classes are lung health aware and that the exercises used are safe.<sup>126</sup> There are also local courses discussed earlier run through the University of Canberra's Health Hub Exercise Physiology program and a Lungs in Action Program through the Bruce CIT.

There are also Internet-based resources which provide some guidance on exercising with COPD,<sup>127</sup> as well as books and other publications which include a range of suitable exercises.<sup>128</sup> Libraries also have DVD and other material that can be borrowed for people to try out. Given the current situation with COVID-19 and the need to physically distance, it may be that new virtual options could be developed. These could be safer and more convenient for people with COPD. These could include on-line guidance through video and Zoom links and telehealth consultations with appropriate health professionals and exercise physiologists or other experts to assist. Some exercise classes for example, in yoga and tai chi, have been operating via Zoom throughout the current lockdowns and these may provide different models for people with COPD.

There is some evidence that breathing exercises, such as purse-lipped breathing, diaphragmatic breathing and yoga with Pranayama breathing techniques can improve exercise tolerance in some people, but not sufficient evidence to support its widespread recommendation for people with COPD.

#### **Optimal nutrition**

Both malnutrition and obesity can occur in people with COPD and these need to be addressed appropriately. There is little evidence that there are effective nutrition interventions to help optimise health in people with COPD beyond eating a nutritious balanced diet and to achieve and maintain a healthy weight.<sup>129</sup> COPD-X includes a series of eating strategies to prevent breathlessness, as that can be a problem and contribute to malnutrition.

- Clear the airways of mucus before eating.
- If supplemental oxygen is used, make sure this is worn while eating.
- Avoid eating large meals, instead eat small nutritious meals and snacks more frequently.
- Avoid drinking with meals.
- Eat slowly.
- Choose softer foods that are easier to chew and swallow, such as mashed potato, soups, bananas.
- Limit foods that can cause bloating, such as beans, onions, cauliflower, soft drinks.
- Rest for at least 15-20 minutes after eating in an upright position.

- In consumers who are underweight, protein and calorie intake can be boosted using high energy, nutrient-rich foods that are easily accessible, such as milk powder, cheese, cream, custard, peanut butter and milkshakes or a nutritionally complete oral supplement (such as Sustagen).
- Referral to a dietitian for individual advice may be beneficial.<sup>130</sup>

#### **Co-existing conditions**

So-called "co-morbidities" are common in people with COPD. These co-existing conditions can include cardiac conditions, stroke, diabetes, depression, polypharmacy, mobility problems. These conditions may or may not interact with each other in one patient, but certainly the existence of two or more of these conditions required a truly whole person, patient centred approach to individual circumstances. This is even more important when any of these are complicated by either other health issues (such as anxiety, obesity or osteoporosis) or socio-economic deprivation.<sup>131</sup>

# **P: Prevent deterioration**

#### Introduction

Under the COPD-X Plan guidelines, the prevention of deterioration includes:

- Smoking cessation to prevent COPD worsening;
- Preventing exacerbations;
- Ensuring people with COPD receive vaccinations against influenza and pneumococcal infection;
- Use of mucolytics (drugs to decrease secretions of mucous and reduce infections) may benefit certain patients with COPD; and
- Long term oxygen therapy has survival benefits for COPD patients with hypoxaemia (low oxygen in the blood).

Smoking cessation has been covered in detail earlier in the C: Section of this chapter<sup>132</sup> and the prevention and management of exacerbations will be dealt with in the X: Section below.

In the current climate, it seems likely that new versions of the COPD-X Plan may include vaccination against COVID-19, and so ensuring that people with COPD are fully immunised each year is an important clinical priority and personal management requirement, when trying to remain well and not have an exacerbation. This can be part of the Regular Review, which is recommended under P9 in the Plan, which states:

Regular review, with objective measures of lung function, health status (COPD Assessment Test (CAT)), consideration of referral to pulmonary rehabilitation and medication review, is recommended. This may reduce complications and the frequency or the severity (or both) of exacerbations and admissions to hospital.<sup>133</sup>

As noted earlier, the efficacy of specific drugs is beyond the scope of this report, so the use of mucolytics will not be discussed here. However, oxygen therapy was an issue raised by consumers during this research, so discussion of this will be briefly included here. Consumers should seek advice from their respiratory specialist and general practitioner in relation to the use of oxygen. The administration of oxygen can be important for some people with COPD. However, the COPD-X Plan guidelines state that:

Although effective, it is a potentially expensive and cumbersome therapy that should only be prescribed for those whom there is evidence of benefit.<sup>134</sup>

As noted at page 31 under the ACT Domestic Oxygen and Respiratory Support Scheme (DORSS) Section, access to government-supported oxygen is governed by the Thoracic Society Clinical Practice Guidelines on Adult Domiciliary Oxygen Therapy.<sup>135</sup>

# **Oxygen Therapy**

Breathing and measuring its effectiveness is very important to people who have lung conditions. This is because lung conditions can affect the ability of a person's body to use the oxygen from the air they breathe. It can also affect their ability to expel carbon dioxide that is a waste product of respiration. The long term inability for someone's body to manage these functions is known as "chronic respiratory failure"<sup>136</sup> and this will reduce their length and quality of life.

#### An explanation of some medical terms

When looking at issues related to therapeutic use of oxygen, it is useful to understand some of the terms and the measures used by clinicians.

Oxygen is necessary for the proper functioning of the body and all its cells. Low levels of oxygen in the blood is called "hypoxaemia" and low levels of oxygen in the tissues is called "hypoxia". When someone gets sick, such as when they get a lung infection, their effective use of oxygen can decline during the course of an illness and they may not be able to absorb enough oxygen from their breathing. This can be called "acute respiratory failure". In this case, they may be treated with supplemental oxygen temporarily to relieve symptoms during the period of short-term illness or while recovering. Long term hypoxaemia and hypoxia is related to more severe COPD and other long term lung conditions, and can cause damage to other organs and reduce a person's capacity to do things and be as well as possible.

Excess carbon dioxide in someone's blood is called "hypercapnia" and this can have a bad effect on many parts of the body. Hypercapnia can also occur if a person has chronic hypoxaemia and they are given too much oxygen.<sup>137</sup>

Even with this very simple explanation of the very complex things that happen in breathing, it is apparent that getting the issues around oxygen right is an important part of good health care, both when someone has an exacerbation and for when their COPD is stable. While oxygen supplementation is important when someone has hypoxaemia, not all people with COPD need oxygen as long term therapy. To determine if the risks of use outweigh the benefits in any particular circumstance, the

person's doctor will measure the oxygen and carbon dioxide in their blood using a blood test called Arterial Blood Gas or ABG.

Measuring the body's oxygen levels can be done in a number of ways. The least invasive method of measuring oxygenation in blood is to use a pulse oximeter, which can just be placed on the person's finger, toe or earlobe. The measure from a pulse oximeter is the  $SpO_2$  - the saturation of peripheral oxygen. It is the fraction of oxygen-saturated haemoglobin relative to total haemoglobin in the blood.

A pulse oximeter has 2 lights and 2 light sensors in it. Oxygenated haemoglobin absorbs more infrared light and deoxygenated haemoglobin absorbs more red light. When the lights pass through the blood in a person's finger, the light sensors measure the amount of red light<sup>138</sup> and infrared light that passes through their finger. The ratio of red light to infrared light gives the oxygen saturation of their haemoglobin. "Normal range" SpO<sub>2</sub> for people without COPD or other lung conditions associated with chronic respiratory failure generally falls between 95-100%. If the pulse oximeter reading is less, supplementary oxygen may be offered in an acute situation until the reading reaches between 92-96%.<sup>139</sup> For someone with COPD, they may normally have a lower level of SpO<sub>2</sub>. If their oxygen level falls below their own normal level or if it is less than 88% in an exacerbation, then supplemental oxygen should be given.<sup>140</sup>

While pulse oximetry is relatively easy to do, it can be inaccurate particularly at lower oxygen saturation levels. When more accurate levels of oxygen or carbon dioxide are required for clinical reasons,<sup>141</sup> arterial partial pressure blood tests are done. Each of these partial pressure test results are presented as a particular pressure, as either mmHg (millimetres of mercury) or kPa (Kilopascals). Saturations are presented in the same way as pulse oximeter reading of SpO<sub>2</sub> – that is as a percentage.<sup>142</sup>

- SaO<sub>2</sub> means arterial oxygen saturation measured by arterial blood gas test. Normal SaO<sub>2</sub> is between 95-100% (averaging about 97%).
- PaO<sub>2</sub> means arterial partial pressure of oxygen and it is a measure of the actual oxygen content in arterial blood. When the body is functioning normally this measure is above 80 mmHg or 10.6 kPa.
- PaCO<sub>2</sub> means the partial pressure of carbon dioxide in arterial blood and it measures the actual carbon dioxide content in arterial blood. Normal values for this measure are 35-45 mmHg.

#### What the evidence says about long term oxygen therapy

Long term oxygen therapy is accepted as standard treatment for people with very low blood oxygen levels ("severe hypoxaemia") – this is at a level of less than 88% SpO<sub>2</sub> or PaO<sub>2</sub> consistently less than 55 mmHg when they are awake but at rest. Long term oxygen therapy has been shown to improve the survival time of some people with COPD with severe hypoxaemia.<sup>143</sup> Such therapy is particularly important where they also have hypoxia related co-existing conditions, such as high levels of haemoglobin ("polycythaemia" – defined as haemoglobin levels are greater than 170g/L), evidence of pulmonary hypertension or right sided heart failure. The COPD-X Plan and the Thoracic Society Clinical Guidelines on Adult Domiciliary Oxygen Therapy recommend that such therapy should be used for at least 18 hours a day to improve longevity.

Sometimes following an exacerbation, people will leave hospital on supplementary oxygen.<sup>144</sup> However, before any decisions are made about whether the need is long term, the COPD-X Plan guidelines stress that the person's need for supplementary oxygen is likely to decline as they recover. They should be reassessed four to eight weeks after initiation of therapy, because people often recover enough to no longer need oxygen long term. In addition, the Plan suggests that before long term oxygen therapy is considered, not only must their condition be stable, but all potentially reversible factors must have been treated and medications optimised, as well as the patient must have stopped smoking at least one month previously.<sup>145</sup>

The goal of long term oxygen therapy is that the flow rate be set to maintain PaO<sub>2</sub> at greater than 60mmHg or 8kPa with pulse oximetry measure of greater than 90% during waking rest and that the therapy be used for at least 18 hours a day.<sup>146</sup> There is strong evidence to support this recommendation. Long term oxygen therapy is usually provided through an oxygen concentrator, but bottled oxygen in a cylinder may also be provided where needed. For people whose hypoxaemia requires long term oxygen therapy, the Thoracic Society Guidelines used in the ACT and the COPD-X Plan both recommend that ambulatory oxygen be made available. This allows consumers to retain the therapeutic duration of oxygen use over a 24 hour period, and to maintain physical and social activity. Consumers who require long term oxygen therapy should be provided with ambulatory oxygen and appropriate equipment sufficient to enable them to have the best quality of life they can.

For people with mild hypoxaemia (89-93% SpO<sub>2</sub>), the evidence does not generally support the use of long term oxygen therapy, even where someone has exercise induced breathlessness. However, there are circumstances where intermittent oxygen use may be considered though the benefits of these intermittent therapies do not seem to be strongly supported by evidence, such as for nocturnal hypoxaemia or some exercise induced conditions. Flying may also require the use of oxygen as well.<sup>147</sup> For those people who have issues with high levels of carbon dioxide, the Plan suggests long term non-invasive ventilation but only in the case of severe, stable COPD.<sup>148</sup>

# **D:** Develop a plan of care

#### Introduction

Under the "D" in the COPD-X Plan guidelines, it is noted that good chronic condition care anticipates the wide range of needs of people with COPD. This requires an integrated care team approach, both when the consumer's COPD is stable and when it is not. It also requires ensuring that consumers have access to good, simple to understand information about how to manage their condition, and if things are not going well, for them to know their "warning signs" what to do and who to contact when. There is strong evidence for positive benefits from effective self-management by consumers. Consumers can also benefit from support groups and other community services.

The three areas set out in this part of the Plan guidelines are, in fact, all elements of what is called best practice person centred care or patient centred coordinated care. This brings evidence-based information to consumers and providers so each can play an appropriate role in the consumer and their carers having the best life they can for as long as possible. Wellbeing, having a good life that you enjoy and having chronic health conditions are not mutually exclusive. Good health care that is there when needed and allows consumers to be active agents in their care and lives can maximise both of these goals.

#### **Care planning**

Effective and best practice care planning focuses on the person and the system through individual care planning and systemic coordination, with the consumer at the centre. In some systems, the term "case management" has been used but consumers generally find this a condescending term, which reduces their role as partners and drivers in their own care and choices. What is wanted is a system where care and service needs are managed, rather than the consumer being seen as someone being managed by the system.

An integrated consumer centred care model requires consumers to be at the centre of the design and creation of the plan and the system, rather than "the condition" or the health professionals involved. It also allows a consumer and their family to decide on what is important for them. A United Kingdom based organisation called National Voices describe what is called person centred coordinated care in the following way:

I can plan my care with people who can work together to understand me and my carer(s), allow me control and bring together services to achieve the outcomes important to me.<sup>149</sup>

#### Individual care planning

The first step in such a process is probably for the consumer to determine what they want to do and how they want to live, and to discuss with their treating team what the impact of their condition(s) may have on their options or preferences and, where possible, how their goals can be accomplished. The initial goal setting must be done by the consumer and they must retain control of the process as much as possible. However, all players who have roles related to necessary care and assistance, need to be actively engaged in the process.

The development of individual care plans is key. As well as initially helping a patient clarify their desired outcomes from health and other services, these can include a shared Action Plan. This can be developed by a consumer and doctor (either specialist or general practitioner) or other health professional involved in their care and acting as a coordinator of the "care team" such as a practice nurse or COPD or respiratory nurse, with other input as needed. It should also include a specific self-care plan for a consumer and possibly their carer, and health and community teambased treatment plans for an individual. Examples of each of these have been developed by Lung Foundation Australia.<sup>150</sup> The following is the front page of the Foundation's *My COPD Action plan* to be completed by the health professional

looking after the consumer with the consumer, as an example of what might be included in such a plan.

#### Figure 7: Lung Foundation Australia My COPD Action Plan

MY DETAILS			
Name		Phone	
Date of birth		Other members of your healthcare team	
Date of influenza immunisation (annual) Date of pneumococcal immunisation		Name	
		Profession	
		If I am unwell, I can call on	for after hours advice
I have a usual amount o	of phlegm/breathle	essness. I can do my us	ual activities.
ACTION: Take your usual C	OPD medicines.		
My FEV, is		l retain CO <sup>2</sup> Yes No	Unknown
Medicine	Inhaler colour	Number of puffs	Times per day
I need to use home oxygen on	setting or L/i	min for hours /da	у.
am coughing more. I ha	ave more phlegm.	It is harder to breathe	than normal.
ACTION: Take your flare-up	medicines. Monitor	your COPD symptoms clos	ely. Call your doctor.
ACTION: Take your flare-up ake puffs of Use a spacer have taken my extra n	medicines. Monitor	vour COPD symptoms clos times every not getting better.	ely. Call your doctor.
ACTION: Take your flare-up Take puffs of Use a spacer have taken my extra n Take action <u>now</u> to manage	medicines. Monitory (reliever) nedicines but I am ge your symptoms.	our COPD symptoms clos times every not getting better. Call your doctor.	ely. Call your doctor.
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Source: https://lungfoundation.com.au/resources/copd-action-plan/

Funding or at least partial funding is available for some of these activities through Medicare. Various Chronic Disease Management items have been available under the Medicare Benefit Schedule (MBS) in various forms since 2005. The items are available to consulting physicians and other specialists and general practitioners involved in the management of chronic conditions for a patient.<sup>151</sup> These include:

- Preparation of a General Practitioner management plan (whether or not the person requires a multi-disciplinary care team);
- Coordination of Team care arrangements when a patient with a chronic or terminal condition also has complex care needs which require a multidisciplinary care team;
- Contribution to a Multidisciplinary Care Plan or to a review of a Multidisciplinary Care Plan, for a patient who is not a care recipient in a residential aged care facility; and
- Review of a General Practitioner management plan or coordination of a review of Team Care Arrangements.

In addition, health practitioners working in a general practice, such as a practice nurse or an Aboriginal Health Worker can be paid under Medicare for monitoring and support services for someone with a Chronic Disease Management Plan on behalf of the general practitioner.<sup>152</sup> Where the general practitioner has been involved in the development of the plan, access to other services from allied health providers can also be included in the plan and paid for by Medicare. These have been gradually extended to cover services required to assist the consumer with one or more chronic conditions and complex care needs. Some of those, who may be of particular relevance to people with COPD, are exercise physiologists, physiotherapists, occupational therapists, psychologists and nurse practitioners. Pharmacists can also be paid by Medicare for Medication Reviews under a Chronic Disease Management Plan authorised by a general practitioner.<sup>153</sup>

The consumer needs to have at least one medical condition that has been or is likely to be present for at least 6 months or is terminal – there are no specific conditions listed. It would seem that a general practice would be able to be involved in both the development and on-going oversight of a COPD Action Plan, involving other health professionals

The basic chronic care management provisions were extended on 13 March 2020 in response to the COVID pandemic, to allow the use of Telehealth for the Chronic Disease Management items. Telehealth monitoring and advice and the use of pharmacies to monitor chronic conditions has also been tested and used in the trial Health Care Home program discussed in Appendix A, where they have been found to be very popular with both providers and consumers. Currently they have been extended to the end of December 2021.<sup>154</sup> Telehealth items were for video-conferencing, but if that was not available, a different item was provided for telephone consultations.<sup>155</sup>

#### System level care coordination centred around consumer needs

As well as individual care plan, arrangements, processes and methods in the organisation of the health and community service functions are needed to ensure that consumer centred and integrated care is actually available to fulfil the plan. The care integration should be as seamless as possible for the consumer and carer, and

meet the standards required under the COPD-X Plan guidelines. This is a familiar issue which has been known about in Australia for many years, as can be seen in Appendix A below. The very slow progress in Australia towards the system goal of patient centred, integrated care at the right time and in the right place is baffling in many ways.

At the moment, the coordination role within these often disparate and unconnected systems most often falls onto carers and family and the consumer, as each part of the disconnected system looks after its own organisational needs first. Navigating these arrangement takes up large amounts of time and energy for the person with COPD and their carer at the time when these resources are most likely to be in short supply because of the physical, mental and emotional consequences of the condition. There needs to be good communication between all the players, and between them all and the consumer and any carer(s) over the life of the plan.

Someone also needs to be given responsibility for ensuring the substance of the care plan is available when needed. In the treatment of people with COPD in the ACT, it is often the case that no-one oversees the linkages and that these are experienced as gateways or blockages by consumers or are simply not known about by them and other parts of the system. A more seamless and appropriate system for consumers is required. This may require different models of service delivery with a range of different health professionals and others providing help do implement the positive potential of the consumer's plan.

For example, consumers often mentioned that they would go to the emergency department if there was nowhere to seek advice after hours and they were worried about a specific issue or symptom. Some said they would contact the ambulance to go to hospital and the paramedics were able to provide assistance including oxygen which often allowed the consumer to be reassured that a visit to hospital was not immediately necessary. However, the COPD-X Plan guidelines note that high levels of oxygen administration in these circumstances may not be the most appropriate treatment, particularly where the person with COPD is experience hypercapnia (high levels of carbon dioxide in their blood).

In those situations where the consumer was sufficiently unwell, they need to be taken to hospital for their condition to be assessed and stabilised<sup>156</sup>. Avoiding hospital if care can be provided outside is likely to be beneficial to someone with COPD. However, there are circumstances where hospitalisation is necessary, appropriate and life-saving<sup>157</sup>. Either way, the person with COPD needs to be sure that they have access to appropriate service options to keep them safe and that if they don't go to hospital, they are still receiving appropriate care.

Another example relates to access to pulmonary rehabilitation. In the case of an ACT person newly diagnosed with COPD, the current system is that pulmonary rehabilitation is provided at the Canberra Hospital and entry to the program is only by referral from a respiratory physician and is only provided once. In NSW, General Practitioners can refer newly diagnosed people to pulmonary rehabilitation which reduces significantly the delay in access compared to ACT consumers. Best practice for consumers under COPD-X<sup>158</sup> and in other jurisdictions is that they have access to pulmonary rehabilitation after any exacerbation involving hospitalisation and at

regular intervals over their life-time, but The Canberra Hospital Policy doesn't allow this at the moment.

It was clear from the consultations and research in this project, that people – doctors, exercise organisers, nurses, other clinicians and consumers and families - were all wanting arrangements to be better. However, there didn't seem to be any coordinating hub for professionals to seek advice or work together, or anyone to help guide consumers to navigate the complex arrangements and gaps in the system. There was not a place where reliable up-to-date knowledge was readily available to consumers and families. The Canberra Lung Life Support Group<sup>159</sup> does as well as it can, but it has no Government funding and its members are often ill. This makes it difficult for them to fill a stronger role, though they were keen to both learn and teach more about what services and information might help and keep them informed about best practice in their care. They also see themselves as a source of information about self-management information.

Many resources and some services are available on the web from Lung Foundation Australia, but as many people with COPD are older, not all of them have access to computers, home printers or the knowledge about how to access information. The situation about lack of current information has been aggravated by COVID-19. Faceto-face groups of all kinds went into the virtual environment to continue their work more safely and this has meant further isolation where people don't have Internet access or need to rely on using Public Library facilities. This resulted in some people missing out on what is available and has made it difficult to identify gaps and unmet or under-met needs, so they can be addressed.

As can be seen from the history of efforts to coordinate or integrate care set out in Appendix A, many of the perceptions of consumers and carers are known and longstanding issues internationally. In some countries many of these issues have been addressed over the past decade reasonably successfully, like in the United Kingdom integrated care program, but in Australia, we appear to have struggled, often at a very basic level.

There have been some good changes at this basic level arising from some of the programs and pilots. For example, in the Interim Evaluation Report 2020 of the most recent trial, the Health Care Home program, the following key points were noted:

Once patient enrolment closed, practices turned their attention to enhancing their model of care. The changes most practices (50% or more) reported they did not have in place prior to HCH but were now working on, included:

- proactive contact with patients to check how they were going
- introducing new roles within the practice
- reassigning components of care from the GP or nurse to a medical assistant
- patients able to communicate by email or secure messaging with the GP or nurse.

Initiatives that practices said they had now implemented or were making good progress implementing were:

- HCH patients able to refill scripts without a GP consultation
- HCH patients able to telephone the practice and talk to the nurse or GP

about their health concerns

• improved systems for follow-up and recall of HCH patients.

The Productivity Commission has also spotlighted innovative examples of chronic care programs that have been implemented at local levels in many parts of Australia. These examples show what can be achieved within what already exists, without waiting for the long overdue broader changes to make these achievements more universal.<sup>160</sup>

What has been learned from all these efforts outlined in Appendix A below are that it is useful for consumers to have a main point of contact and coordination, probably through a general practice. Practice nurses seem to be a popular way to enable this. As noted earlier the number of practice nurses has increased dramatically over the past two decades. Unfortunately, unlike many places overseas, respiratory nursing is not yet recognised as a nursing specialty in Australia, but it is in New Zealand. There is a Special Interest Group – Respiratory Nursing under the Thoracic Society of Australia and New Zealand,<sup>161</sup> which was contacted as part of this research. The chair of that Special Interest Group Jane Cotter, who practises in NSW noted:

Despite not being recognized as a discrete specialty, almost every Public Hospital in NSW has access to a Clinical Nurse Consultant in Respiratory – I am a Nurse Practitioner in CardioRespiratory managing clients with Chronic Respiratory Conditions and Chronic Heart Failure and I have counterparts in most Local Health Districts. I work across the acute setting into CardioPulmonary Rehab outpatient programs and into the Community and collaborate with GP practices.

This is something the Special Interest Group is currently working on – to have their specialist knowledge recognised as it is in the United Kingdom, United States of America and New Zealand. The work of the nurses in New Zealand, who are also members of the Thoracic Society covering Australian and New Zealand, has included the development of a New Zealand Adult Respiratory Nursing Knowledge and Skills Framework, which was revised in 2016. This provides a detailed resource for looking at the knowledge and skills of nurses who may wish to fulfil such roles here.<sup>162</sup> They also provide a training resource for general practice nurses through Lung Foundation Australia. Ms Cotter also noted that prior to COVID:

The Lung Foundation h[ad] a group of Registered Nurses who go to GP practices to teach Practice Nurses and GP's about the various inhalers available and COPD in general.

It appears at the moment that the program has not been active during COVID, but they have been seeking people who will be able to assist again in the future.<sup>163</sup> It may be possible also to discuss with the Thoracic Society the possibility of running on-line webinars to assist skill up practice nurses as part of implementing the ACT reforms.

Other options include on-line training opportunities for nurses to learn more about being a COPD nurse through an 18 module on-line training program.<sup>164</sup> There is also an on-line 4 hour continuing professional development course run by the Australian

College of Nursing.<sup>165</sup> For peer support for people working as nurses in COPD there is a COPD Nurse Network run by Lung Foundation Australia<sup>166</sup> and the Special Interest Group – Respiratory Nursing noted above under the Thoracic Society of Australia and New Zealand.<sup>167</sup> The Flinders University Chronic Disease Management Courses also appear to offer training to help health professionals and others to support people to self-manage their chronic condition.<sup>168</sup>

#### **Self-management strategies**

In 2009 the Final Report of the National Health and Hospitals Reform Commission noted the importance that consumers attached to having a health system which supported self-management:

There is not sufficient recognition of our own capacity to take action and improve our own health, supported by our families and communities. We heard about the vital importance of recognising and nurturing self-management to support people to take greater control in managing their health issues:

"Self-management is what most people with long term conditions do – they manage their daily lives and cope with the effects of their condition as best they can, for the most part without any intervention from professionals".

"A cornerstone of reform should be a proactive model for health coaching and care management for citizens which supports selfmanagement and drives a 'smarter patient' able to take increased accountability of their own health."

"The concept of a partnership highlights the need for health care professionals to understand and respect the role of the carer in achieving maximum health outcomes for their patient."

These ideas, bubbling out of our submissions, speak to the reality that good health is not something that is simply 'done' to us through our interactions with the health system. We must be active participants in our own good health, working in partnership with our health professionals, our carers and families. But this has to occur within the context of our social and economic circumstances and the communities in which we live. The aim has to be to encourage and support everyone to achieve their maximum health potential, regardless of their age or whether they have a chronic illness or a disability.

These sentiments have echoed through much of the evaluation work set out in Appendix A. The COPD-X guidelines discuss the evidence for self-management both in terms of quality of life and morbidity, mortality and frequency of exacerbations.<sup>169</sup> The studies show varying results on almost all measures, and because the methods are so different in the trials (called "heterogeneity"<sup>170</sup>), the COPD-X Plan says it is difficult to be sure which elements of self-management or self-management support are most effective in actually improving health. There is mixed evidence with some trials delivering good results. Despite the variable results, the COPD-X Plan states that "patients may benefit from self-management support" and classify the evidence

to support this as Level 1, which is the best and highest level on the NHMRC evidence gradient and make it a strong recommendation.

A specific issue with some of the work on self-management is that often health professionals (doctors and nurses) describe themselves as "self-managing the patient". This phrase undercuts the real difference between a planning process for someone to have things often done *to them* and a self-efficacy strategy to help the person do the things *for themselves*, where possible. Self-efficacy teaching helps people learn skills to use themselves in achieving their best health and life outcomes. Self-efficacy also shifts control to the consumer as much as possible, and in a chronic condition, this sense of control regained is very important for many consumers. Diagnosis often brings a sense of loss of control which can be addressed by engagement in active self-management.

In the work of the Productivity Commission in its Case Study work on Innovations in care for chronic health conditions, its chapter looking at self-management says: "Self management of chronic conditions is essential, but it can be hard to achieve". The report defines self-management skills in a broad sense:

Self management skills include problem solving, decision making, finding and using resources, forming partnerships with health care providers and taking action (Lorig and Holman 2003). In a practical sense, this often means people monitoring their symptoms, taking medications as prescribed, following lifestyle advice to the best of their ability and knowing where and when to seek professional assistance if their health starts to deteriorate.

Professor Kate Lorig, who developed the Chronic Disease Self-Management Program with her team from the Stanford Patient Education Research Center in the United States uses a similarly broad definition and uses the following analogy to help people understand the concept and the power dynamics in active self-management:

Both at home and in the business world, managers are in charge. They don't do everything themselves; they work with others, including consultants, to get the job done. What makes them managers is that they are responsible for making decisions and making sure that their decisions are carried out.

As the manager of your illness, your job is much the same. You gather information and hire a consultant or team of consultants consisting of your physician and other health professionals. Once they have given you their best advice, it is up to you to follow through. All chronic illnesses need day-to-day management.

Managing a chronic illness, like managing a family or a business, is a complex undertaking. There are many twists, turns, and midcourse corrections. By learning self-management skills, you can ease the problems of living with your condition.

The key to success in any undertaking is (1) defining the problem, (2) deciding what you want to do, (3) deciding how you are going to do it, and (4) learning a set of skills and practicing them until you master

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them. Success in chronic disease self-management is the same. In fact, mastering such skills is one of the most important tasks of life.<sup>171</sup>

It is also important to understand that some consumers may be less interested or capable of active self-management immediately, or they may not want to be actively engaged in self-management. On the other side of the partnership, the Productivity Commission notes that many clinicians have little training or experience in supporting self-management and so mistakenly see themselves as "self-managers" rather than assistants to the consumer. The Commission's key findings about supporting people with chronic conditions to actively self-manage are:<sup>172</sup>

Supporting people with chronic conditions to be more active in their health management can be a low cost way to keep people healthier and prevent hospitalisations. However, support is not always available for those who need it.

For many people with chronic conditions, better health can start through very small steps to help them take a more active role in their health management. For more vulnerable people, greater investment is likely to be required, but large improvements in health outcomes can be achieved.

Successful initiatives bring health care and support to people in a proactive, timely and accessible way, instead of leaving them to manage — or fail to manage — on their own.

The graphic in Figure 8 from their Case Study summarises the report's conclusions in this area.<sup>173</sup>

# Figure 8: Productivity Commission's graphic on supporting people to manage their chronic conditions

Self- management is essential but it is not always supported (section 2.1)	<ul> <li>Many clinicians have little training or experience in supporting self-management</li> <li>Limited financial incentives to offer support for consumer self-management</li> <li>Wide variation in consumers' capacity to self manage</li> </ul>
Simple tools can make a big difference (section 2.2)	<ul> <li>Simple plans and reminders help people to manage their conditions</li> <li>Self-management support programs have proven benefits</li> </ul>
Supporting people on their terms (section 2.3)	<ul> <li>Successful innovations bring health care and support to people in a proactive, timely and accessible way</li> <li>For more vulnerable people, greater investment is likely to be required, but large improvements in health outcomes can be achieved</li> </ul>
Working towards partnerships with consumers (section 2.4)	Partnerships between consumers and health care providers are essential for effectively managing chronic conditions

Source: https://www.pc.gov.au/research/completed/chronic-care-innovations, page 44

Another possible source of assistance for self-management or advice for consumers who are happy to use the Internet or telephone is the Respiratory Nurse service offered through Lung Foundation Australia<sup>174</sup> and their information and support services may also be able to assist.<sup>175</sup>

Not only is it important for people with COPD to look after their physical health, but it is also important to look after their mental health. People with COPD often have depression and anxiety associated with their diagnosis and symptoms. Lung Foundation Australia has established a Mind Matters program which includes webinars and videos to assist people with self-management techniques to improve and maintain their mental health. Readily accessible through YouTube, at 27 July 2021 there were 7 videos, including a brief introductory video, a 50 minute webinar and 5 videos of between 5-10 mins each on a range of techniques and practices for self-compassion and mindfulness.<sup>176</sup> Lung Foundation Australia also provides up-to-date materials tailored to specific current events like COVID-19.<sup>177</sup>

Self-management may also include getting assistance with home chores and personal support. Some of these are funded through the National Disability Insurance Scheme (NDIS) and some are funded through Aged Care Packages, or if someone is not eligible for these systems, they can be arranged privately. There are
useful resources on Self-management in home care available on the COTA website <u>https://www.cota.org.au/information/self-management-in-home-care/</u> including a Consumer Guide to Self-management and a Consumer Self-management Toolkit.

#### Peer support and community services

As well as the Canberra Lung Life Support Group, which is discussed in more detail above at page 34, there are Peer Programs run by Lung Foundation Australia that include an online support network, face-to-face peer support groups, telephone support groups and one-on-one peer matching.<sup>178</sup> Lung Foundation Australia's Live your Best Life Blog is also a source of information and hope for consumers wanting to know more.<sup>179</sup> There are a significant number of on-line communities for people with COPD and they provide important support and information to people who may be isolated, as was discussed in the work of HCCA member Caroline Polak Scowcroft referred to earlier.<sup>180</sup>

Peer support can also come through participation in community activities, like exercise<sup>181</sup> or recreational classes and educational activities. For example, people over 50 can join the University of the Third Age (U3A) which is very active in Canberra. Other supports can come from general programs available to people, such as assistance with using computers to allow older consumers who may not be familiar with using the Internet.<sup>182</sup>

One of the issues for the Canberra Lung Life Support Group is that they do not receive any government funding and their members are sometimes ill, so they have difficulty doing a range of activities which may assist their members. This is something which could be discussed with the Group to see how best they can be assisted to fulfil their aim of providing support, particularly in the context of COVID-19 and some of the limitations arising from that in particular.

# X: Manage eXacerbations

The COPD-X Plan states that an exacerbation

is characterised by a change in the patient's baseline dyspnoea, cough and/or sputum that is beyond normal day-to-day variations, is acute in onset, and may warrant a change in regular medication or hospital admission.

Avoiding exacerbations and hospitalisation are key strategies to help people with COPD remain well and to slow progression of the condition. This is why immunisations against influenza, pneumococcal infection and COVID-19 are all essential interventions for people with COPD and their clinical partners. Similarly, avoiding air pollution and other airway irritations like smoke<sup>183</sup> are important.

The Plan notes that exacerbations are often worse in winter, where colds and other viral conditions are more prevalent in the community.<sup>184</sup> Unfortunately, people are often unaware that going out into the community can expose vulnerable people to these conditions, which are likely to have a much greater impact on their health than the unthinking person from whom they catch the cold or viral condition. Several consumers noted that the isolation periods arising from COVID-19 last year reduced

the infections they caught from others, with many avoiding any exacerbations or admissions to hospital last year.

## Avoiding or minimising hospitalisation where possible

Avoiding unnecessary hospitalisations are important for several reasons:

- Hospitals are centres of infection for people who are admitted. The nosocomial infections in hospitals can be harder to treat, and thus a greater threat to a sick person, if they have existing vulnerabilities from an underlying chronic condition. Avoiding unnecessary admissions reduces the risk of hospital acquired infections. It is possible to provide health services under different models that can ensure people get access to the drugs and care they might need, in their homes, such as Hospital in the Home.
- When people are admitted to hospital, they often don't move very much and this can lead to physical deconditioning, which occurs quite quickly. Such deconditioning can result in poorer health at discharge and the need for additional pulmonary rehabilitation after discharge. The longer the period of inactivity, the greater the degree of deconditioning. This can be a particular issue where someone experiences the need for a period in intensive care (ICU). Not only is this a signal of more significant immediate illness, but the period of inactivity while in ICU is more intense than on the ward and may mean that recovery of prior function may be delayed or not possible.

One useful way of minimising unnecessary hospital admissions is to have pre-planned steps for consumers in their Action Plan about what to do if they start to experience an exacerbation. Lung Foundation Australia provides a useful checklist and algorithm for primary health carers to work with a person with COPD to better avoid and manage exacerbations. This helps the person with COPD to understand what to do and when to do it if they begin to feel unwell. Lung Foundation Australia includes the stepwise plan as part of its kit for helping primary care health professional. Not only does it help the consumer and provider complete the COPD Action Plan but it acts as an education tool for safer decision-making using a stepwise process, which is evidence-based from the COPD-X Plan.

#### Figure 9: Lung Foundation Australia Managing Exacerbations Algorithm

## ALGORITHM **MANAGING** EXACERBATIONS



Publication date: October, 2018

Source: <a href="https://lungfoundation.com.au/resources/managing-exacerbations-algorithm/">https://lungfoundation.com.au/resources/managing-exacerbations-algorithm/</a>

Figure 10: Managing a COPD Exacerbation Checklist

# MANAGING A COPD EXACERBATION CHECKLIST

This Checklist is supported by the use of STEPWISE MANAGEMENT OF STABLE COPD available at www.lungfoundation.com.au/stepv

IN HOSPITAL				
	Inhaled bronchodilators	Use short-acting bronchodilators as appropriate to improve symptoms.		
	Oral corticosteroids	Consider use of oral corticosteroids (5 days, oral route, short course, no tapering) to reduce readmission and length of stay.		
	Oral antibiotics	Prescribe if clinical features of infection are present. Oral antibiotics are preferred over IV antibiotics.		
	Oxygen therapy	Aim for oxygen saturation of 88-92% in hypoxaemic patients.		
	Non-invasive ventilation (NIV)	Consider NIV to reduce length of stay and mortality due to hypercapnic respiratory failure.		
	Physiotherapy	Encourage physical activity and introduce the most appropriate airway clearance technique for patients who have difficulty clearing sputum.		
	Smoking status	Review current status and implement smoking cessation strategies including referral to Quitline (13 78 48).		

#### PRIOR TO LEAVING HOSPITAL

Smoking cessation support	Ensure smoking cessation strategies are in place.	
Spirometry	Perform and/or arrange spirometry.	
Inhaler technique	Check technique and ensure patient is able to use each inhaler correctly.	
COPD Action Plan	Provide or update where one already exists.	
Pulmonary rehabilitation	Refer to pulmonary rehabilitation, discuss benefits and encourage attendance.	
General Practitioner	Arrange follow-up appointment with nominated GP. Prepare and provide summary of inpatient treatment to nominated GP.	
Medication	Reassess adherence and step up therapy as appropriate e.g. consider need for inhaled corticosteroids and adding second long-acting bronchodilator.	
Support services	Establish support required at home or place of residence.	
COPD Information Pack	Provide patient with Lung Foundation Australia COPD Information Pack.	

#### **ONGOING CARE 1-4 WEEKS POST DISCHARGE**

Smoking status	Review status and implement smoking cessation strategies.
Medication	Reassess adherence and review inhaler technique.
COPD Action Plan	Review and discuss as appropriate.
Vaccinations	Ensure influenza and pneumococcal vaccinations are up to date.
Pulmonary rehabilitation	Ask about attendance and re-refer if necessary.
Oxygen therapy	Review need for long term oxygen therapy (LTOT) in patients discharged from hospital on oxygen.
Referral	Consider need for referral for additional services including peer support.
	Smoking status Medication COPD Action Plan Vaccinations Pulmonary rehabilitation Oxygen therapy Referral

Refer to STEPWISE MANAGEMENT OF STABLE COPD resource available at www.lungfoundation.com.au/stepwise.



especially cardiovascular disease, anxiety, depression, lung cancer and osteoporosis.

#### Refer patients to Lung Foundation Australia for

information and support FREECALL 1800 654 301

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Lung

Foundation

Australia

Lung Foundation Australia has a range of resources to promote understanding of COPD and assist with management. Contact details of local pulmonary rehabilitation programs and Support Groups are also available.

It is recommended that you consult the suite of COPD-X Guidelines for further information when using this Checklist (COPD-X Plan: Australian and New Zealand Guidelines for the Management of COPD; COPD-X Concise Guide; Stepwise Management of Stable COPD. Visit www.copdx.org.au for further details.

Source: https://lungfoundation.com.au/resources/managing-copd-exacerbation-checklist/

## **Reducing exacerbations and readmissions**

The COPD-X Plan guidelines includes a two-page table of ways of reducing hospital utilisation, many of which involve wise use of medicines, but others of which are non-invasive ventilation, use of hospital in the home, having a multi-faceted care plan and pulmonary rehabilitation. It also includes teaching consumers about airway clearance techniques so they can use them to prevent exacerbations, and supported discharge programs as well as practices to ensure medication compliance. Both the last actions reduced readmission by almost half.<sup>185</sup>

Lung Foundation Australia has developed a Managing a COPD Exacerbation Checklist covering the journey of a patient once admitted to hospital to the weeks after returning to home, based upon all the evidence in the COPD-X. The guidelines include this checklist.<sup>186</sup> The checklist is above and includes steps to be taken in hospital, before leaving hospital and on-going care outside in the community after someone has experienced an exacerbation. It shows the importance of proper primary care follow-up in the immediate post-exacerbation period.

#### Home management

The COPD-X Plan guidelines suggest that when hospital beds are in great demand in winter, an option worth exploring that is supported by evidence, is to provide multidisciplinary care in the home. Hospital in the Home in the ACT has been in its early stages for some time, but it may be a model worth exploring more deeply in the broader reform process. The evidence shows it significantly reduce the risks of readmission within 1-6 months of a home-delivered treatment.

# Conclusions

Combined together:

- the existence of the very up-to-date COPD-X Plan guidelines and the support and educational materials and support available from Lung Foundation Australia;
- the increased policy, funding and professional interest in ensuring that the health systems and health professionals can deliver properly coordinated and integrated care that is patient centred;
- the growing utility of My Health Record to connect a consumer's health information across a range of health services;
- the greater availability of practice nurses and allied health services through general practice planning and Medicare funding;
- the existence of the Capital Primary Health Network to assist with communication and training across the broader primary care landscape; and
- the extensive experiences that have been developed over the past 3 decade with the goal of piloting coordinated and integrated care practices, especially in chronic conditions;

provide a strong framework for sensible innovation and reform for people with COPD as set out in the Executive Summary and Recommendations. There is also much that can be done to ensure people have prompt and timely access to health

assistance, including early diagnosis, active and evidence-based care planning and treatment and better management to prevent exacerbations and hospitalisations from exacerbations. Collection of useful, timely data can also inform our own community evidence base and planning.

In addition, there are extensive resources available in the broader community, which can supplement the specific Lung Foundation Australia programs, like exercise classes, social and educational sessions which can address people's social isolation, as well as options for in-home support services to help people manage better if their activities of daily living are impacted by their COPD. However, often people don't know about these community supports and activities. Having a single place to look would be a welcome development for professionals and consumers alike.

The Canberra Lung Life Support Group provides a much under-utilised and underfunded point of information for consumers and assistance should be made available to help them better achieve their potential as a voice for consumers and families affected by COPD as well as a source for up-to-date information.

The health system also has an important role to play in ensuring up-to-date information is available about what is available in the ACT community to support the wellbeing of people with COPD and other chronic conditions and to ensure they are supported in their health and life journey as seamlessly as possible. This is not currently available.

# **APPENDIX A:**

# Coordinated care for people with complex care needs: a brief history and lessons from two decades of trials

#### Introduction

The issue of poor coordination of care across health and community services that can provide assistance to all people with chronic health conditions has been a longstanding problem in Australia. This is partly because of the split financial responsibilities between the Commonwealth and the States/Territories across the different "layers" of health.<sup>187</sup> If anything, this has become even more complicated with the introduction of the National Disability Insurance System and the Aged Care system, which recreate the same split government financial layers across disability and aged care arrangements. For example, if someone has a disability or is an elder and is receiving NDIS or Aged Care Package support already and they are recovering from an acute event, like an injury, and they require rehabilitation and physiotherapy or occupational therapy assistance, it is often far from clear which services they can access and who pays.

These issues have been known about for a long time and from time-to-time efforts have been made to develop better ways to address them. In the ACT after self-Government and in Australia more broadly, the divisions of funding between Commonwealth, States and Territories and between portfolios and programs have often created illogical barriers and disorganised arrangements from the perspective of consumers. Models in other places overseas have funding mechanisms, which make integration easier, for example collective funding for all health care and some community services provided to a geographical area to service a particular community across all their associated health and community service needs. Such an example is Trust-based funding under the National Health Service in the United Kingdom.<sup>188</sup>

#### The National Health Strategy 1990-1993

In Australia, there has been awareness of the need for better systems of care and funding to meet the needs of the community for more than 30 years and a long history of trialling more integrated service delivery and funding options. The National Health Strategy, conducted by Ms Jenny Macklin, under the then Health Minister Brian Howe between 1990-1993, remarked upon this issue. In the first Background Paper *Setting the Agenda for Change,* Macklin noted that:

Problems exist with the integration of health service at many levels. Integration is not an end in itself. Rather the lack of integration becomes an issue if it means that the best mix of services is not able to be delivered in a way that is both convenient for users and providers and produces best patient outcomes.

. . .

The focus of medical and hospital care on the treatment of acute episodes of illness ... means that people with chronic ill-health may not have their needs well met. Several factors work against the integration of services required to manage the wellbeing of a person with a chronic problem such as arthritis. Payment mechanisms for doctors are not based on meeting the whole needs of patients. Doctors are rewarded more for ordering a test or prescribing a drug, than for lengthy counselling or for ensuring that patients are aware of the network of social supports available to them. People with chronic problems need their treatment provided through coordination of a range of care-givers, including for example, physiotherapists, pharmacists, and home nursing staff. Managing this continuum of care takes a great deal of time and it can be frustrating to both providers and consumers when no quick solution is available. <sup>189</sup>

It is of concern to realise that almost 30 years later, much of the care provided to people with COPD still has these same issues. Even where there have been small incremental improvements, today we are still at the pilot evaluation stage of the Health Care Home project which is yet another trial of a model to address the lack of integration and coordination.

Some of the more endemic issues such as workforce barriers and professional "turf" disputes, remain as impediments to more seamless and accessible care. Going on to discuss how the organisation of the health care workforce and its funding created problems for a more integrated approach in 1990, she quotes from Dr Sidney Sax<sup>190</sup> in 1984, who said that "modern healthcare has been described as 'a strife of interests masquerading as a contest of principles'." While again there has been progress in some boundary disputes, there remain many barriers that impact on more integrated care for consumers, such as the limited roles allowed for nurses in the local Walk-in Centres for people with chronic conditions Sax's comment was made almost 40 years ago, so it might be hoped that we had made more progress.

If there is any doubt about the longevity of these problems, a 1991 Issues Paper of the National Health Strategy *The Australian Health Jigsaw: integration of health care delivery* describes what it sees as a recurring theme in Australian health care:

The need for improvements in the relationships between services, programs and levels of Government has been recognised by many commentators and review over the past fifteen years.<sup>191</sup>

Proposals for change were made to address the known concerns, and the Issues Paper suggested reforms that are inter-related and have recurring themes, which were:

- Incentives for best practice care and continuity of care;
- Incentives for substitution of the most effective and most efficient service;
- Improved consumer responsiveness; better targeting of resources; maintenance of accountability, alongside increased flexibility.

#### **Coordinated Care Trials – Round 1**

The Council of Australian Governments in February 1994 "endorsed the need for reform of health and community services so as to better meet people's care needs and provide better value for money for taxpayers". There were two parts to these

trials: a general part and a specialised Aboriginal and Torres Strait Islander part, which had different aims and different funding arrangements.

The primary purpose of the general Coordinated Care Trials was:

To develop and test different service delivery and funding models and determine the extent to which the [Coordinated Care Trial] model contributes to:

- Improved client outcomes;
- Better delivery of services, which are individually and collectively more responsive to clients' assessed needs; and
- More efficient ways of funding and delivering services.

The hypothesis to be tested by these trials was "that coordination of care of people with multiple service needs, where care is accessed through individual care plans, and funds pooled from existing Commonwealth, State and joint programs, will result in improved individual client health and wellbeing within existing resources."<sup>192</sup> The secondary hypotheses being tested related to what might affect the achievement of the primary hypothesis, which were:

Hypothesis 2: The extent of substitution between services within a trial pool; Hypothesis 3: The range of service included in the trial and the size of the pool;

*Hypothesis 4: the characteristics of the clients to whom services are provided; Hypothesis 5: the quality of the clinical and service protocols;* 

Hypothesis 6: the characteristics of the care coordination function;

Hypothesis 7: the characteristic of trial administrative arrangements; Hypothesis 8: the extent to which health consumers are partners in the planning of the coordinated care trial, the development of care plans and

empowered through the coordination process.<sup>193</sup>

Nine Coordinated Care general trials were established across Australia including the ACT, where the trial was called Care Plus.<sup>194</sup> These included around 16,500 consumers with complex and chronic care needs in 9 places throughout Australia. In addition to the ACT, these covered the northern suburbs of Adelaide in South Australia; central, southern and western suburbs of Adelaide and the Eyre Peninsula in South Australia; Southern Tasmania; the Illawarra area of NSW; Hornsby and Kuring-gai areas of Sydney NSW; the north eastern suburbs of Melbourne Victoria, outer suburbs of south-east Melbourne; and Northern suburbs of Brisbane in Queensland. People enrolled were mostly aged over 65 and were considered to be socio-economically disadvantaged.<sup>195</sup>

The method of the study used control and intervention groups, and overall the intervention group with coordinated care did not perform better than the control group. The overall results of the general trials were complicated and mixed. Generally, the trials could not fund coordinated care from the savings generated by reduced hospitalisations. Only 3 of the 9 general models showing a significant reduction in hospitalisations for the intervention groups compared to the control groups. Two main models emerged from the trials: one strengthening the role of GPs and the second adding the role of a coordinator. However, most of the general trials

showed that participants in intervention groups most valued the extra coordination aspect of their care.<sup>196</sup>

There were 4 additional trials in round 1, which focussed on coordinated care in Aboriginal and Torres Strait Islander populations.<sup>197</sup> These trials were centred around 5 locations: 2 in the Northern Territory at Katherine West and the Tiwi Islands; 2 in Western Australia at Bunbury and Perth; and one in Wilcannia in NSW<sup>198</sup>. These trials were distinguished from the general trials in the following ways listed in the evaluation of these trials:

- They targeted a broader cross section of people not just those with complex illness. Three of the four trials involved the whole community, consequently there was a strong focus on community empowerment and on establishing the organisational and financial capacity that was already established in the general trials;
- The Aboriginal and Torres Strait Islander trials received additional funding for health care services, whereas the general trials were limited to the pool of existing funds ie the general trials were required to operate with existing/historical resources (with the exception of infrastructure funding that all trials received from the Commonwealth);
- The trials did not aim for service substitution between the acute, primary health care and community sectors as did the general trials coordinated care was not expected to deliver whole of system cost efficiencies but was intended to provide for more flexible use of funds; and
- A major common aim of the Aboriginal and Torres Strait Islander trials was to increase access to comprehensive primary health care services and to services that were more relevant to the holistic health care needs of Aboriginal and Torres Strait Islander people.<sup>199</sup>

The Aboriginal trials thus had different goals compared to the general trials and in the evaluation of these trials, they were found to have "made considerable progress in all aspects of the intended program of reform".<sup>200</sup> Details of the trial outcomes are listed under access to health services, appropriateness of services at an individual and population level, organisational capacity, funding and administration, and empowerment. In particular, an analysis of the care coordination frameworks adopted by the trials showed that care coordination had similar basic elements: Client assessment, care plan development, care plan implementation and care plan review/change. However, each of the trials differed in how these were operationalised, with variables including:<sup>201</sup>

- The personnel who fulfilled the tasks associated with the care coordination role (three models emerged, the general practitioner alone, the general practitioner with support, another person, not the general practitioner, as the coordinator);
- The support they receive in undertaking their associated tasks;
- The nature of the training and remuneration they receive for their roles;
- The nature of their employment (eg independent practitioners, sub-contractors or employees) and the associated implications for accountability;
- Their relationship to budgets;
- The mechanisms involved in assessment of clients; and

• The structure of the care planning process.

These are important issues to consider in the development of any future work, both in the broader community, as well as with Aboriginal and Torres Strait Islander communities. The Evaluation of these trials stressed that:

There is no doubt that the program achieved many positive effects, including:

- The building of capacity within communities and trial organisations to implement health system reforms;
- A formal care management system that focused on an individual's health, and which enabled the individual's care needs to be identified and appropriate care services to be planned and delivered;
- The provision of basic infrastructure and resources for training and additional clinical support staff for health centres that many other health systems take for granted;
- The provision of proven public health and community development measures to the targeted communities as a consequence of adequate funding;
- The delivery of good clinical practices to individuals as a result of increased funding; and
- The effective transfer of decision-making responsibility to community-based organisations.<sup>202</sup>

All the trials included components of assessment, care planning and service coordination. "Of these, service coordination seemed to have the most impact and warranted further study, especially in terms of which clients benefit most."<sup>203</sup> In many ways, the results of the trials encapsulated the difficulties faced by consumers in accessing the care they needed when they had a chronic condition or complex health issues.

## Coordinated Care Trials – Second Round 2002-2005

Funding for additional Coordinated Care Trials was provided in the 1999-2000 Commonwealth Budget. The primary purpose of the additional trials was "to build on the lessons of the earlier trials and to test different service delivery and funding options".<sup>204</sup> The ACT did not participate in the second round trials. There were two "mainstream" trials and three Indigenous trials, "each with a unique design plan for the funding and delivery of coordinated care".<sup>205</sup> The trials were conducted between 2002-2005, with the evaluation extending into 2007. Two prime aims for the Evaluation were to effectively capture data on whether the trials achieved:

- A whole of population approach, which encompasses improvement to access and delivery of primary health care services and improvements in the coordination of care for the community generally; and
- The coordination of care for those with chronic and complex needs.<sup>206</sup>

The outcomes were significantly better overall, with the Evaluation listing them into 5 categories: outcomes for participants, outcomes for communities, efficiency and effectiveness, features associated with success and implications for the future of

coordinated care – usefulness, sustainability and transferability of the trial models. Findings of particular relevance to this project were that the involvement of primary care providers was critical, that primary care involvement engagement also needed to be at a more "overall level" like our Primary Health Networks, which have developed since these trials, but that a separate coordinator role from the general practitioner often had the best outcomes.<sup>207</sup> The development of practice nurses was in its infancy when these trials began, and they now provide a possible way of achieving a better way of having good primary care involvement and avoiding general practitioner overload.

## National Health and Hospital Reform Commission

The year after the release of the Evaluation of the second round of coordinated care trials in 2007, the Rudd Government established the National Health and Hospitals Reform Commission to provide "a blueprint for design and a plan of action to tackle current and future challenges in the Australian health system". This was one of a significant number of reform initiatives not only in health but more broadly.<sup>208</sup> In its Final Report in mid 2009, the Commissioner's said:

All Australians suffering from chronic illness require a range of health services delivered by a variety of health professionals across the spectrum of primary, secondary and tertiary health care. The health system for a person with chronic disease is complex. People often fall between the 'care gaps' and 'handovers' between care givers.

A person with a chronic illness or serious condition in Australia,

"... by and large, has a miserable existence in trying to organise their health care and prevent further deterioration."

Unless we are better able to reduce pre-disposing risks and connect the care journey, chronic disease will impose a substantial and increasing burden on our health system and, importantly, reduce quality of life for many Australians and their families.<sup>209</sup>

Following the release of this Report, the Commonwealth Government committed to these reforms. In December 2009, the Council of Australian Governments agreed that its central priority for 2010 was that:

long-term health reform was required to deliver better services for patients, more efficient and safer hospitals, more responsive primary healthcare and an increased focus on preventative health.

While Labor remained in power at the Commonwealth level, the broader National Health Reform Agenda progressed towards "structural reform [that] will change the way health services are delivered through better access to high quality, integrated care designed around the needs of the patient and a greater focus on prevention, early intervention and provision of care outside of hospital, where and when people want it."<sup>210</sup> However, some of the financial changes proposed hit political road blocks<sup>211</sup> and progress was slow in implementing more coordinated care approaches. However, progress continued in the area of primary health care.

#### National Primary Health Strategy 2010 and National Primary Health Care Strategic Framework 2013

In May 2010 a National Primary Health Strategy was released by the then Health Minister Nicola Roxon, entitled *Building a 21st Century Primary Health Care System*. Key Priority Area 2 under that Strategy was better management of chronic conditions. The listed key direction for change was:

Improved continuity and coordination of care, particularly for those with chronic disease, including a comprehensive national approach to chronic disease management, tailored and delivered locally.<sup>212</sup>

#### This was to begin with people with diabetes and the strategy announced that:

As part of delivering the National Health and Hospitals Network, the Australian Government will invest \$449.2 million over four years to transform the way Australians with diabetes are treated. ... Under these new arrangements, patients diagnosed with diabetes will have the option of enrolling with a GP practice of their choice to receive high quality coordinated care and help them access a range of additional services (such as a dietician or podiatrist). Enrolled patients will be assisted to maintain and improve their health, with GP practices for the first time being rewarded for meeting performance benchmarks.

The practice described in the Strategy is close to what became known later as a Health Care Home, and the initial focus on diabetes was seen as a first step, but an ambitious one. The strategy expected that by 2012-13, more than 4,300 or 60% of all General Practices would have signed onto the program in its first year of operation and over a quarter of a million consumers with diabetes would be voluntarily enrolled in a personalised care program by 2013-14.<sup>213</sup>

This plan was followed in April 2013, by the Standing Council on Health, made up of all State and Territory and Commonwealth Health Ministers, adopting the National Primary Health Care Strategic Framework, under the National Health Reform Agreement. This Framework was not to overtake the Strategy, but to help its enactment. It was to be the basis for bilateral plans, jointly developed between the Commonwealth and States/Territories to address the issues of most importance to each jurisdiction.<sup>214</sup> Strategic Outcome 1 of the Framework was to:

build a consumer-focused integrated primary health care system – with primary health care service being integrated and coordinated within the primacy health care sector and the wider health system. The services would be tailored to meet consumer needs and preferences and are appropriate to the needs of specific population subgroups.<sup>215</sup>

The Framework activity was to involve the Medicare Locals and Local Hospital Networks, consumers and providers to develop joint service plans to coordinate availability of services. Of particular relevance to this project were the following potential actions listed:

1.5 Medicare Locals will work with consumers, communities, health service providers and others to examine innovative care coordination and/or case management arrangements for people with complex chronic conditions, which focus on secondary and tertiary prevention, improving health outcomes and literacy, and reducing avoidable hospitalisations.

1.6 Promote the role of consumers as partners in the health care team and empower them to make decisions about their own health and social needs.

1.7 Develop and promote innovative 'pathways through care' models which support more integrated and seamless care for consumers.

1.8 Manage more complex, urgent cases within the community by facilitating the development of integrated and ambulatory urgent care services in areas of need.<sup>216</sup>

Following a change of Government in September 2013, the new Government under Tony Abbott dismantled many of the reform elements. This Budget also saw the proposed introduction of a \$7 co-payment to see a bulk-billing doctor (defeated in the Senate) and the closure of Medicare Locals, as well as \$80 billion cuts to health and education over the next 10 years,<sup>217</sup> and the coordinated and integrated care issues fell victim to this broader political process for a time.

However, there were other moves afoot, with the concept of medical practices as patient centred medical homes being developed in a number of other countries with significantly different funding systems, including the United States of America.<sup>218</sup> This model was also being discussed and developed in Australia.<sup>219</sup> Similar models involving integrated, collaborative, person centred care, including patient self-management were also been developed in the United Kingdom, which has over the past 8 years successfully implemented the system across England.<sup>220</sup>

## Primary Health Care Advisory Group 2015

The problems that had now been discussed in Australia for almost two decades had not disappeared. In July 2015, the then Health Minister Sussan Ley formed the Primary Health Care Advisory Group in recognition of the continued problems of lack of coordination and integration of care for consumers:

Australia's health system is under increasing pressure to provide better quality, affordable and accessible health care, based on universal access to Medicare. A long term strategy is needed, to offer a better patient journey for those with chronic and complex health conditions; to investigate innovative care and funding models; better recognition and treatment of mental health conditions; and greater connection between primary health care and hospital care.<sup>221</sup>

The role of the Primary Health Care Advisory Group was to examine opportunities for the reform of primary health care in improving the management of people with complex and chronic health conditions. In December 2015, the Group produced its Final Report entitled *Better outcomes for people with chronic and complex health conditions.*<sup>222</sup> The report was released publicly by the Health Minister and the then Prime Minister Malcolm Turnbull at the end of March 2016.<sup>223</sup> The core of this Report

was to reform primary care for people with chronic and complex conditions, using the idea of Health Care Homes. In his Letter of Transmittal to the Minister, the GP Chair Dr Steve Hambleton said:

Central to the reform is the establishment of Health Care Homes, which provide continuity of care, coordinated services and a team based approach according to the needs and wishes of the patient. This new approach is supported by new payment mechanisms to better target available resources to improve patient outcomes.<sup>224</sup>

#### Health Care Home Program Trial & other developments 2015-2021

The Report proposed a model for the Health Care Home, which included support from the Primary Care Networks (PHNs), 31 of which had been established on 1 July 2015 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.<sup>225</sup>

The role of PHNs was, among other things, to establish and promote local clinical health pathways and to provide training and support for the participants. The trial was to include 65,000 Australians in up to 200 practices. An additional \$21 million was committed to support the rollout of trials from 1 July 2016.<sup>226</sup> The key features proposed in the Report for a Health Care Home are set out below,

**Voluntary patient enrolment** with a practice or health care provider to provide a clinical 'home-base' for the coordination, management and ongoing support for their care.

*Patients, families and their carers as partners in their care* where patients are activated to maximise their knowledge, skills and confidence to manage their health, aided by technology and with the support of a health care team.

**Patients have enhanced access** to care provided by their Health Care Home in-hours, which may include support by telephone, email or videoconferencing and effective access to after-hours advice or care.

**Patients nominate a preferred clinician** who is aware of their problems, priorities and wishes, and is responsible for their care coordination.

*Flexible service delivery and team based care* that supports integrated patient care across the continuum of the health system through shared information and care planning.

A commitment to care which is of high quality and is safe. Care planning and clinical decisions are guided by evidence-based patient health care pathways, appropriate to the patient's needs.

**Data collection and sharing** by patients and their health care teams to measure patient health outcomes and improve performance. <sup>227</sup>

In 2016 prior to the commencement of the Health Care Home pilot, in a parallel process, the NSW Agency for Clinical Innovation worked independently on the idea of patient centred Medical Homes (a term used in other countries as well) and Healthcare Neighbourhoods.<sup>228</sup> The Agency uses a diagram created by Dr Tony Lembke of the Australian Centre for the Medical Home,<sup>229</sup> to represent the Patient centred medical home and the broader Healthcare Neighbourhood, in which the consumer lives.



Figure 11: Medical Home and Health Care Neighbourhood

Source: <u>https://www.aci.health.nsw.gov.au/nhn/patient-centred-medical-home-model/what-is-the-patient-centred-medical-home-model</u>.

Their website *Navigating the Healthcare Neighbourhood*<sup>230</sup> provides great resources for both consumers and providers who want to do things in a more integrated way, including an excellent video, explaining what the patient centred medical home model is in simple terms for both providers and consumers.<sup>231</sup>

Getting the trials started took some time and the actual trial of Health Care Homes model only started on 1 October 2017. The General Practices and Aboriginal Controlled Community Health Services were to be responsible for coordinating the care of consumers with chronic or complex conditions. This program was promoted in many ways, including videos.<sup>232</sup> In December 2018, the Commonwealth Government extended the trial by 18 months, including extending enrolment of consumers until 30 June 2019 or to a patient cap of 12,000.<sup>233</sup>

In August 2018 community pharmacists were brought into the trial under the Sixth Community Pharmacy Agreement Health Care Homes evaluation.<sup>234</sup> The role of the pharmacies under the Health Care Home trial related to medication management, including:

- Medication reconciliation and assessing the patient's medicines regimen;
- Identifying any potential medication related issues and agreeing on medication management goals;
- Developing a medication management plan in collaboration with patient and their Health Care Home;
- Providing regular follow-up reviews with the patient (in consultation with the referring Health Care Home practice);
- Providing support services for the more complex patients, such as dose administration aids, blood glucose monitoring, blood pressure monitoring and asthma management planning.<sup>235</sup>

The 2020 Interim Evaluation includes a significant list of lessons from the 2019 and 2020 Interim Evaluations.<sup>236</sup>

The Health Care Home Program ended on 30 June 2021, and the Evaluation is due for completion by late 2021.

# **APPENDIX B:**

# The Broader Context of the National Health Reform Agreement and Chronic Conditions

#### Introduction

Many of the issues identified by both consumers and providers, in this Report and others, were about the fractured, disconnected nature of current treat and support services for people with COPD in Canberra and region. The problem of a lack of coordinated or integrated care for people with complex conditions has been recognised since the early 1990s and solutions have been trialled since the first Coordinated Care trials in the late 1990s. This is discussed in more depth in Appendix A above.

This changed and developing medical and scientific understanding of the prognosis for people with COPD and the ability to improve their health, wellbeing and longevity has been accompanied by the development of other frameworks and plans designed to shape the health care system which are likely to achieve better outcomes for people with COPD. Some of these frameworks and plans are detailed below. The National Health Reform Agreement 2020-25, signed by all Australian governments on 29 May 2020, is another important part of the change journey needed in the ACT and nationally.

#### Australian Health Ministers' Advisory Council Frameworks

The Australian Health Ministers' Advisory Council (AHMAC) Frameworks are two national frameworks established by AHMAC which were precursors to the development of some national efforts to achieve better health outcomes for people with COPD. These are:

- The Aboriginal and Torres Strait Islander Health Performance Framework; and
- The National Strategic Framework for Chronic Conditions.

Exactly how these Frameworks will continue to be operationalised in the post COVID-19 context is unclear. Both the Council Of Australian Governments (COAG) and AHMAC have ceased to exist and have been replaced by National Cabinet and National Cabinet Reform Committees,<sup>237</sup> including one on health. Given the relationship between the ongoing National Health Reform Agreements and these Frameworks, it seems likely they will continue to be implemented in some form.

# Aboriginal and Torres Strait Islander Health Performance Framework

The Aboriginal and Torres Strait Islander Health Performance Framework commenced in 2006 and was designed in consultation with Aboriginal and Torres Strait Islander stakeholder groups to promote accountability, inform policy and research' and foster informed debate about the health of Indigenous Australians.<sup>238</sup> Annual Reports continue to be made under this Framework.<sup>239</sup> The Health Performance Framework (HPF):

... is made up of 68 measures across three levels, or tiers:

Tier 1: Health status and outcomes

Tier 2: Determinants of health

Tier 3: Health system performance

Each HPF measure represents a health-related concept that is explored in detail, using various indicators drawn from relevant data sources and research.

The HPF illustrates change that has occurred for the measures, and draws implications for further improvement. It also explores differences within the Indigenous population by age, geography and other characteristics. This helps identify what is working well and how to better target policy and services to meet the needs of Indigenous Australians.<sup>240</sup>

Reporting under this Framework helps monitor the Closing the Gap health targets and the Implementation Plan goals for the Aboriginal and Torres Strait Islander Health Plan 2013-2023. The 2020 Report notes that:

A key theme from the research is the importance of culturally competent service delivery, and the need to partner with and share decision-making with Aboriginal and Torres Strait Islander people in the design of services and programs that affect them.

While there are organisations across sectors that provide culturally competent services to Indigenous Australians, the HPF highlights the crucial role of Aboriginal Community Controlled Health Services. These services provide comprehensive, culturally appropriate and safe primary health care services for Indigenous Australians throughout their lives.

The HPF also highlights where mainstream services are not adequately meeting the needs of Indigenous Australians, or where there are service gaps.

The most recent national Framework Report in 2020 shows that while smoking rates among Aboriginal people are declining across all age groups,<sup>241</sup> lung conditions (including COPD and asthma and other non-cancer respiratory conditions) were significant causes of death for Indigenous people nationally. The Report noted that 1,400 Indigenous Australians were recorded as dying from respiratory conditions between 2014-12018 and this was the fourth leading cause of death (9% of all deaths of Indigenous Australians). 62% of these deaths were from COPD, 17% from pneumonia and influenza and almost 5% from asthma.<sup>242</sup> The age-standardised death rate for Indigenous Australians with COPD between 2014-2018 was three times as high as that for non-Indigenous Australians (70 compared to 24 deaths per 100,000 population).<sup>243</sup> In 2018-19, almost 1 in 3 Indigenous Australians had a long term respiratory condition (lasting longer than 6 months).<sup>244</sup>

While respiratory conditions are more prevalent among Indigenous Australians in non-remote areas, the hospitalisation rate is higher in remote and very remote areas.<sup>245</sup> Often residents of remote and very remote areas need to go to larger urban centres off their country to access specialist services. This geographical

complication often means people don't access services or that services aren't readily available until they are very ill.

In 2020, a separate Framework report for the ACT was produced<sup>246</sup> but the ACT data is not included in many areas in the national report.. There are a number of reasons for the exclusions, which are detailed in a number of Australian Institute of Health and Welfare (AIHW) publications on data quality and comparability.<sup>247</sup> Some of these are historical, some are related to identification inconsistencies, and some appear to be gaps in the availability of information required by the AIHW.

It may be that there are factors that explain the differences between the national data on COPD and the ACT data, given the urban situation of most Aboriginal and Torres Strait Islander who reside in the ACT, . It may also be that some of the necessary data is not collected, or collected well, in the ACT. An analysis of the quality and accuracy of the ACT's respiratory data under the Aboriginal and Torres Strait Islander Health Performance Framework and of COPD data collected in the ACT, is beyond the scope of this project. Given the likely frequency of COPD in the ACT community, better data and the capacity to look critically at this data in policy terms is important if we are to address the issues faced by consumers. This is also a priority under the national reform agenda in the National Health Reform Agreement 2020-2025 below.

## **National Strategic Framework for Chronic Conditions**

The Australian Health Ministers' Advisory Council (AHMAC) produced the National Strategic Framework for Chronic Conditions following extensive consultation with the community, government, health professionals and consumers. It was endorsed by the Council of Australian Governments (COAG) Health Council in 2017. The framework recognises the significant impact of chronic conditions on the wellbeing of the Australian community and sought a different way forward.

Our new approach recognises that there are often similar underlying principles for the prevention and management of many chronic conditions. As such this Framework moves away from a disease-specific focus and better considers shared health determinants, risk factors and multimorbidities across a broad range of chronic conditions.<sup>248</sup>

The Framework defines chronic conditions as:

- Having complex and multiple causes;
- Affecting individuals either alone or as co-existing conditions;
- Usually have a gradual onset, although they can have sudden onset and acute stages;
- Occur across the life cycle, although they become more prevalent with older age;
- Can compromise quality of life and create limitations and disability;
- Are long term and persistent, and often lead to a gradual deterioration of health and loss of independence; and

• While not usually immediately life threatening, are the most common and leading cause of premature mortality.<sup>249</sup>

The Framework is designed around 3 objectives. Objective 1 proposes a focus on prevention; Objective 2 seeks to provide efficient, effective and appropriate care to support people with chronic conditions to optimise quality of life; Objective 3 seeks to target priority populations, which are defined quite broadly:

Priority populations include, but are not limited to: Aboriginal and Torres Strait Islander people; people from culturally and linguistically diverse backgrounds; older Australians; carers of people with chronic conditions; people experiencing socio-economic disadvantage; people living in remote, or rural and regional locations; people with disability; people with mental illness; and people who are, or have been, incarcerated.

#### The AHMAC report stated that the Framework:<sup>250</sup>

- moves away from a disease-specific approach;
- identifies the key principles for the effective prevention and management of chronic conditions;
- supports a stronger emphasis on coordinated care across the health sector;
- acknowledges and builds on work already in place that supports chronic conditions;
- complements state-based, national and international policy for chronic conditions;
- accommodates existing and new strategies and policies without changing the responsibilities of the Australian or state and territory governments;
- acknowledges the important role that the health sector may take as a leader and advocate in working with other sectors to address the social, economic and environmental determinants of health; and
- provides flexibility to accommodate future and emerging priorities and allows for innovative solutions for the prevention and management of chronic conditions.

A summary of the Concept Map of the Framework in Figure 12 sets out identified strategic priority areas, principles and "enablers". The Strategic Priority areas set out under the Framework align with many of the elements of the COPD-X Plan guidelines and pick up many of the issues noted by consumers and providers in the research undertaken in this project. This includes, for example, reduction in smoking, the encouragement of appropriate physical activity, integrated consumer centred care processes, assistance to promote self-management and the measurement of progress towards specified outcomes. Addressing the absence of adequate quality data across the area of COPD is a priority, to make judgments about where resources are to be most effectively spent.

The importance of better data collection throughout the system was clear in the research for this Report. There are large gaps in publicly available data at the ACT level. It is impossible to create a best practice system with appropriate and efficient use of resources without data being available in as close to real time as possible to clinicians and consumers. For example, how do we know which admissions to hospital might have been avoided and which ones were needed to preserve the life and health of someone with COPD, unless this is being monitored and analysed by the clinicians involved in a patient's care? Without such information, how do we avoid hospital admissions and treat exacerbations in a more focussed way for someone with COPD?





Source: https://www.health.gov.au/resources/publications/national-strategic-framework-forchronic-conditions at page 7.

## **National Strategic Action Plan for Lung Conditions 2019**

The National Strategic Action Plan for Lung Conditions 2019 was released in February 2019. Its purpose was to engage all levels of government in Australia to "begin to reduce inequality and the burden of lung disease on individuals and society" (REF). This echoes the direction of the Framework for Chronic Conditions (see above), by seeking to develop programs across a range of conditions which affect lung health and looking for solutions which can improve lung health across a range of conditions. It also starts to consider the need for more integrated care where someone has co-existing conditions.

In the Foreword of the Action Plan, Professor Christine Jenkins, Chair of Lung Foundation Australia, noted that lung conditions are the second highest cause of death in Australia (behind heart disease.) She went on to say that 1 in 3 Australians live with a lung condition and one in seven Australians over the age of 40 are diagnosed with COPD.<sup>251</sup> She noted that lung conditions had several compounding inequities associated with them:

Those who are already burdened by socio-economic disadvantage are also disproportionately affected by occupational and environmental determinants of respiratory ill health and are less able to access appropriate care. Beyond these startling facts, we also know that people with lung disease face something entirely different from other chronic and terminal illnesses: discrimination. Australians living with a lung condition feel isolated and discriminated against. Discrimination and stigma prevent the achievement of good outcomes following a diagnosis – because people feel ashamed and delay seeking help.

The Action Plan aims "to improve the lives of all Australians through better lung health". It focusses on:

- Addressing health determinants and risk factors for lung conditions to enhance the lung health of the Australian community;
- Optimising quality of life for people with lung conditions;
- Redressing areas of poorer health outcomes and unmet need ;
- Action at the wider health-system level to ensure real and lasting improvement for all Australians; and
- Delivering tangible improvements in health outcomes, equity and economic benefits.

The Plan has eight priority lung conditions, which are:

- Lung cancer;
- Chronic Obstructive Pulmonary Disease (COPD);
- Bronchiectasis;
- Respiratory infection;
- Interstitial Lung Diseases (ILD);
- Occupational lung diseases;
- Respiratory lung disease overlap (multiple lung diseases in one person); and
- Rare lung conditions, including Cystic Fibrosis (CF).

Consistent with the National Chronic Diseases Framework discussed above, the Action Plan recommends an approach which includes all lung conditions. This is because there are common elements in these which can be helped in similar ways. It also looks at how to treat any co-existing conditions in an integrated person-centred manner. The Plan's eight guiding principles are drawn directly from the National Chronic Disease Framework. They are:

- Equity
- Collaboration and partnerships
- Access
- Evidence-based
- Person centred approaches
- Sustainability
- Accountability and transparency
- Shared responsibility

The Action Plan also identifies priority populations:

- Aboriginal and Torres Strait Islander people
- People living in regional, rural and remote areas
- People who smoke
- Workers currently and previously exposed to occupational dusts, gases, fumes and vapours
- People from culturally and linguistically diverse backgrounds
- People experiencing socio-economic disadvantage

The Plan sets out a strategic approach to reducing the burden of lung conditions and improving lung health. Of significance here is the inclusion of stigma and discrimination, where people have been seen to be "to blame" for their ill-health. This occurs in other conditions where people are told that their condition arises from "lifestyle" factors that, presumably they could have changed. This shaming language and attitudes contribute to poor mental health and do nothing to help people to maintain their wellbeing over their life span. They also ignore the complex factors that underlie behaviours and the strong influence of socio-economic determinants in these conditions.

Like the National Chronic Conditions Framework, the Plan shows a way forward that is more centred on the complex lives of consumers, where their condition and its management is an important element, but around which their lives continue. Often messages from the health system are very mixed and people can become exhausted with the management tasks required for their condition. Simplifying and assisting people with self-management can benefit everybody as well as the health system.



## Figure 13: National Strategic Action Plan for Lung Conditions

Source: <u>https://www.health.gov.au/sites/default/files/documents/2019/09/national-strategic-action-plan-for-lung-conditions\_0.pdf</u> at page 10

# National Health Reform Agreement 2020-2025

## **Objectives**

The National Health Reform Agreement 2020-2025 commits all States, Territories and the Commonwealth to "improving health outcomes for Australians by providing better coordinated and joined up care in the community and ensuring the future sustainability of Australia's health system". The objectives of the Agreement are (REF):

The Commonwealth and the States will work in partnership to implement arrangements for a nationally unified and locally controlled health system which will:

- a. improve patient outcomes, patient experience and access to services, including by focussing on what matters most to patients, supporting innovative models of care and trialling new funding arrangements (Schedule C);
- b. improve the provision of GP and primary health care services, including Aboriginal and Torres Strait Islander community-controlled health organisations, and the effective integration of health services at a local and national level (Schedule C);

- c. improve care coordination for people with chronic and complex needs, building on the activities set out in the 2017 Bilateral Agreements on Coordinated Care and incorporating them into relevant long-term health reforms (Schedule C);
- d. improve the safety and quality of health services through continuation of hospital pricing reforms agreed by COAG in 2017 (Schedule A);
- e. improve standards of clinical care, including through guidance from the Australian Commission for Safety and Quality in Health Care (ACSQHC) (Schedule B);
- f. improve accountability and performance reporting on the health system through the Australian Health Performance Framework and supporting national performance indicators (Schedule D);
- g. improve local accountability and responsiveness to the needs of communities through continued operation and collaboration between Local Hospital Networks (LHNs) and Primary Health Networks (PHNs) (Schedule E);
- h. work effectively with the aged care and disability support systems to deliver better outcomes (Schedule F);
- i. improve access to and use of data to support service delivery and improved patient outcomes (Schedule C);
- j. improve public hospital efficiency through the use of ABF based on a national efficient price (Schedule A);
- ensure the sustainability of funding for public hospitals by increasing the Commonwealth's share of public hospital funding through a 45 per cent contribution to the costs of growth, subject to the operation of the National Funding Cap (Schedule A); and
- I. maintain transparency of public hospital funding through the National Health Funding Pool (Schedule A).

#### **Principles**

Similarly, Schedule C – Long Term Health Reform Principles – includes principles that prioritise prevention and helping people manage their health across their lifetime, through empowering people through health literacy, and prevention and wellbeing<sup>252</sup>. Given the difficulties in obtaining the sort of public data on COPD that might help enable a better system, the schedule also makes enhanced health data a priority to drive best practice and performance that uses data and research. The six Reforms set out in Schedule C are summarised as follows:<sup>253</sup>

- empowering people through health literacy person centred health information and support will empower people to manage their own health well and engage effectively with health services;
- prevention and wellbeing to reduce the burden of long-term chronic conditions and improve people's quality of life;
- paying for value and outcomes enabling new and flexible ways for governments to pay for health services;
- joint planning and funding at a local level improving the way health services are planned and delivered at the local level;

- enhanced health data integrating data to support better health outcomes and save lives; and
- nationally cohesive health technology assessment improving health technology decisions will deliver safe, effective and affordable care.

#### Aims and how the Agreement might help consumers

The Agreement provides potential for moving to address some of the issues identified by consumers and providers in this research, in an area of high health priority and significant fragmentation. COPD and other related lung conditions might be able to be seen as "low hanging fruit". COPD also has the advantage of the solid best practice guideline which already exist to guide the way. There is potential for using this Agreement and each of the Frameworks and Plans discussed above in this Chapter to positively effect change in the ACT in relation to COPD treatment. This is also illustrated by the aims set out by the Agreement in Clause 27.<sup>254</sup>

27. Further, the Parties agree the reforms aim to:

- a. reorient the health system around individuals and communities and improve patient outcomes and experiences while considering the impacts on patients, carers and their families;
- b. achieve better integrated patient centred care that is evidence-based and incentivises innovation;
- c. emphasise patient empowerment, particularly through co-design of services, collaboration with providers and expanded use of new and existing technologies; and
- d. promote equitable access to high quality health care and reduce disadvantage for all Australians, including for Aboriginal and Torres Strait Islander people and those living in regional and remote areas.

#### **Other relevant National work**

Further national work has also been continuing in relation to chronic condition management, as set out in the Productivity Commission's March 2021 Case Study *Innovations in care for chronic health conditions*.<sup>255</sup> This study, among other things emphasised that chronic conditions incur high levels of recurrent health costs. COPD incurred 0.8% of national recurrent health costs, involving expenditure of \$977m in 2015-16,<sup>256</sup> 46.8% in public hospitals and 8.1% in private hospitals and 26% on pharmaceutical benefits costs. Most importantly, it documents innovative ways people have tried to create more integrated care within the current system, rather than waiting for other transformations which might make it easier. As the history of efforts towards more integrated care set out in Appendix A, the achievements of the examples set out in the Productivity Commission's 2021 study are no small feats. They demonstrate that real change is possible, even in the short term.

The Australian Commission on Quality and Safety in Health Care's *Fourth Australian Atlas of Healthcare Variation* released this year also showed that across Australia there were significant levels of avoidable hospitalisations, in relation to COPD,<sup>257</sup> including in the ACT. However, because this data relies on the quality of data collected, it can be difficult to determine how accurate this data is and how to use it to address inappropriate variations. Even knowing how many people have been

formally diagnosed with COPD in the ACT and how many people we should be seeking to identify through case finding are in many ways, are educated guesses at the moment.

However, both of these documents read alongside the COPD-X Plan and Lung Foundation Australia's other documents, and the broader work to pursue more appropriate and integrated consumer centred care for all people with chronic conditions contribute to developing a pathway forward from where we are now.

# Endnotes

- <sup>1</sup> Different people use different words to describe consumer centred care, including person centred care, patient and family centred care, client centred care, and patient centred care.
- <sup>2</sup> HCCA Position Statement on consumer centred Care <u>http://www.hcca.org.au/about-hcca/position-statements.html</u>
- <sup>3</sup> Polak Scowcroft CE. Life's Changing Landscape *Exploring the experiences of people with COPD: An analysis of public narratives*. 2013 A thesis submitted to the Faculty of Graduate Studies, in partial satisfaction of her Master of Arts Disability Studies, University of Manitoba, Winnipeg, Canada (Polak Scowcroft Thesis 2013).
- <sup>4</sup> See, eg, the National Medication Safety Breakthrough Collaborative <u>http://www.health.vic.gov.au/vmac/medicationsafety.htm</u>.
- <sup>5</sup> See, eg, The Breakthrough Series: IHI's Collaborative Model for Achieving Breakthrough Improvement. IHI Innovation Series white paper. Institute for Healthcare Improvement 2003 Boston. (Available on <u>www.IHI.org</u>)
- <sup>6</sup> See <u>https://www.health.nsw.gov.au/Value/Pages/collaborative-commissioning.aspx</u>.
- <sup>7</sup> Lung Foundation Australia. COPD the Basics. <u>https://lungfoundation.com.au/resources/copd-the-basics-booklet/</u>: see pages 6-7, which also includes Figures on page 7 explaining the differences between each of the diseases under the COPD umbrella.
- <sup>8</sup> Yang IA, George J, Jenkins S, McDonald CF, McDonald V, O'Brien M, Smith B, Zwar N, Dabscheck E. *The COPD-X Plan: Australian and New Zealand Guidelines for the management of Chronic Obstructive Pulmonary Disease 2021*. Version 2.63, February 2021. Lung Foundation Australia and Thoracic Society of Australia and New Zealand. (COPD-X Plan 2021). Available at: <u>https://copdx.org.au/copd-x-plan/https-copdx-org-au-wp-content-uploads-2021-04-copdx-v2-63-feb-2021\_final-published-pdf/</u>: at pages 24-25.
- <sup>9</sup> Halpin DMG, Celli BR, Criner GJ et al. The GOLD Summit on chronic obstructive pulmonary disease in low and middle income countries 2019 *International Journal of Tuberculosis and Lung Diseases,* volume 23, issue 11, pages 1131-1141, at page 1311.
- <sup>10</sup> Global Initiative for Chronic Obstructive Lung Disease (GOLD) 2021, Global Strategy for the Diagnosis, Management and Prevention of Chronic Obstructive Pulmonary Disease (2021 Report), page 1: Accessed 23 May 2021 at <u>https://goldcopd.org/wpcontent/uploads/2020/11/GOLD-REPORT-2021-v1.1-25Nov20\_WMV.</u> (GOLD 2021)
- <sup>11</sup> Halpin et al. 2019. See endnote 9: at page 1132.
- <sup>12</sup> Fletcher C. Peto R. The natural history of chronic airflow obstruction. 1977 British Medical Journal, 25 June1977, pages 1645-1648: at <u>https://www.bmj.com/content/1/6077/1645</u>.
- <sup>13</sup> Jordan RE. Cheng KK. Miller MR. Adab P. Passive smoking and chronic obstructive pulmonary disease: cross-sectional analysis of data from the Health Survey for England. 2011. *BMJ Open*: volume 1, issue 2, e000153. <u>http://doi:10.1136/bmjopen-2011-000153</u>.
- <sup>14</sup> COPD-X Plan 2021 see note 8: at pages 20-21.
- <sup>15</sup> Recent research shows that even in Australia, having home wood heating or gas cooking and heating, particularly but independently of tobacco smoke, with poor ventilation is linked to a higher incidence of persistent asthma and more rapid decline in lung function from middle-age. See: Dai X. Buli DS. Perret JL. Lowe AJ. et al. Exposure to household air pollution over 10 years is related to asthma and lung function decline. 2021 *European Respiratory Journal*. volume 57, issue 1, https://doi.org/10.1183/13993003.00602.
- <sup>16</sup> See Dai et al 2021, at note 15.
- <sup>17</sup> Benjamin JT, Plosa EJ, et al. Neutrophilic inflammation during lung development disrupts elastin assembly and predisposes adult mice to COPD. 2021 *Journal of Clinical Investigation*, volume 131, issue 1, pages 1-15: this research is indicative in mouse models but requires more research

in human experience, though there already appear to be an association. See: <u>https://doi.org/10.1172/JCI139481</u>.

- <sup>18</sup> GOLD 2021: See note 10: at page 8-9.
- <sup>19</sup> See eg, Drummond MB. Kirk GD. HIV-associated obstructive lung diseases: insights and implications for the clinician. 2014 *Lancet Respiratory Medicine*, volume 2 (July), issue 1, pages 583-592. See also: Byrne AL. Marais BJ. Mitnick CD. et al Tuberculosis and chronic respiratory disease a systematic review. 2015. *International Journal of Infectious Diseases*, 1 March 2015, volume 32, pages 138-146.
- <sup>20</sup> COPD-X Plan 2021 see note 8: at page 19.
- <sup>21</sup> COPD-X Plan 2021 see note 8: at page 19.
- <sup>22</sup> COPD-X Plan 2021 see note 8: at page 19.
- <sup>23</sup> COPD-X Plan 2021 see note 8: at page 19.
- <sup>24</sup> COPD-X Plan 2021 see note 8: at page 20.
- <sup>25</sup> COPD-X Plan 2021 see note 8: see page 74 and section 07. Comorbidities (pages 74-89) more generally.
- <sup>26</sup> Royal Australian College of General Practitioners (RACGP). *RACGP aged care clinical guide* (*Silver Book*), 5<sup>th</sup> Edition, Part A Multimorbidity. This part was published in October 2019. The earlier editions of this publication were called *Medical care of older persons in residential aged care facilities* and the RACGP noted in its overview that : "This fifth edition builds on the remarkable foundation set by the previous four editions, and is retitled the *RACGP aged care clinical guide* (*Silver Book*) to reflect the increasing prevalence of older people choosing to live their old age in the community, or remaining in the community for longer." <a href="https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/silver-book/part-a.">https://www.racgp.org.au/clinical-resources/clinical-guidelines/key-racgp-guidelines/view-all-racgp-guidelines/silver-book/part-a.</a>
- <sup>27</sup> RACGP 2019 at note 26 at page 2.
- <sup>28</sup> See, eg, Jain VV. Allison DR, Andrews S. et al. Misdiagnosis among frequent exacerbators of clinically diagnosed asthma and COPD in absence of confirmation of airflow obstruction. 2015 *Lung.* Volume 194, issue 4, pages 505-12. doi: 10.1007/s00408-015-9734-6 Epub 2015 Apr 29. Spirometry of consumers who had been clinically diagnosed as having asthma or COPD, where they had frequent hospital admissions, showed that one-third of them had neither COPD or asthma and have been misdiagnosed.
- <sup>29</sup> Liang J. Abramson MJ, Zwar NA. et al Diagnosing COPD and supporting smoking cessation in general practice: evidence-practice gaps.2018 Medical Journal of Australia, volume 208, issue 1, 15 January 2018, pages 29-34: This study showed more than a third of consumers diagnosed with COPD in general practice did not have COPD, and 17% of people who had not been diagnosed with COPD previously were shown by spirometry to have the condition.
- <sup>30</sup> See, eg: Willis O. 2020 Poor air quality caused by bushfire smoke posing serious risk for healthy people too, health experts warn. ABC Health and Wellbeing 7 January 2020. <u>https://www.abc.net.au/news/health/2020-01-07/prolonged-bushfire-smoke-creates-new-health-risks/11844934.</u>
- <sup>31</sup> Newspaper stories from that time indicated there was a substantial impact on existing people with COPD across the eastern seaboard of Australia. For example, <u>https://www.goulburnpost.com.au/story/6579216/copd-sufferer-impacted-by-bushfire-smoke-and-lack-of-health-staff/</u>. Community organisations like Lung Foundation Australia also warned people of the dangers from smoke for people with COPD. <u>https://lungfoundation.com.au/news/bushfirecrisis-lung-health-update/</u>.
- <sup>32</sup> Department of Health 2019. Policy and Regulatory approach to electronic cigarettes (Ecigarettes) in Australia – Principles that underpin the current policy and regulatory approach. 28 November 2020. <u>https://www.health.gov.au/resources/publications/policy-and-regulatoryapproach-to-electronic-cigarettes-E-cigarettes-in-australia</u>.
- <sup>33</sup> Therapeutic Goods Administration Prohibition on importing E-cigarettes containing vaporiser nicotine. 17 November 2020 <u>https://www.tga.gov.au/behind-news/prohibition-importing-Ecigarettes-containing-vaporiser-nicotine</u>.

- <sup>34</sup> Centers for Disease Control and Prevention. Outbreak of Lung Injury Associated with the use of E-cigarette, or Vaping, Products. See : <u>https://www.cdc.gov/tobacco/basic\_information/E-cigarettes/severe-lung-disease.html.</u>
- <sup>35</sup> <u>https://www.cdc.gov/tobacco/basic\_information/E-cigarettes/Quick-Facts-on-the-Risks-of-E-cigarettes-for-Kids-Teens-and-Young-Adults.html</u>.
- <sup>36</sup> US Department of Health and Human Services. E-cigarette Use Among Youth and Young Adults: A Report of the Surgeon General. 2016 Atlanta, GA: US Department of Health and Human Services, CDC; 2016. See: Ecigarettes.surgeongeneral.gov/documents/2016\_SGR\_Exec\_Summ\_508.pdf.
- <sup>37</sup> Bahtouee M, Mleki N. Nekouee F. The prevalence of chronic obstructive pulmonary disease in hookah smokers. 2018 May, *Chronic Respiratory Disease*, volume 15 issue 2, pages 165-172.: see <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5958464/</u>.
- <sup>38</sup> Kumar AN, Soo CI et al. Marijuana "bong" pseudomonas lung infection: a detrimental recreational experience 2018 Respiratory Case Reports, volume 6, issue 2:pages 1-3: <u>https://onlinelibrary.wiley.com/doi/epdf/10.1002/rcr2.293</u>.
- <sup>39</sup> Ribeiro LIG, Ind PW. Effect of cannabis smoking on lung function and respiratory symptoms: a structured literature review. 2016 Primary Care Respiratory Medicine, volume 26, <u>https://www.nature.com/articles/npjpcrm201671</u>. See also Gracie K, Hancox RJ. Cannabis use disorders and the lungs. 2020 Addiction. Volume 116, issue 1: see DOI: <u>10.1111/add.15075</u>.
- <sup>40</sup> Australian Institute of Health and Welfare (AIHW) Alcohol, tobacco and other drugs in Australia. Web Report – last updated 16 April 2021: see <u>https://www.aihw.gov.au/reports/alcohol/alcohol-tobacco-other-drugs-australia/contents/priority-populations/younger-people</u>.
- <sup>41</sup> <u>https://www.aihw.gov.au/reports/chronic-respiratory-conditions/copd/notes.</u>
- <sup>42</sup> The sources of data and data are listed on the Data Sources tab, which is include in the Data tab at <u>https://www.aihw.gov.au/reports/chronic-respiratory-conditions/copd/data.</u>
- <sup>43</sup> Australian Institute of Health and Welfare (AIHW). 2014. Coronary Heart Disease and chronic obstructive pulmonary disease in Indigenous Australians. AIHW Canberra Cat No. IHW 126: see page iv Summary.
- <sup>44</sup> Australian Commission on Safety and Quality in Health Care (ACSQHC) 2021. The Fourth Australian Atlas of Health Care Variation. ACHSC Sydney 2021. (4<sup>th</sup> Atlas of Variation) <u>https://www.safetyandquality.gov.au/publications-and-resources/resource-library/fourth-</u> australian-atlas-healthcare-variation-2021.
- <sup>45</sup> See note 42, at Table 3.2, which compares smoking rates from 1980 until 2018 with death rates from COPD, which shows some of delay over time, between stopping smoking and declining COPD death rates per 100,000 deaths.
- <sup>46</sup> <u>https://www.aihw.gov.au/reports/australias-health/tobacco-smoking</u> : at Figure 3 Proportion of people who are daily smokers aged 18 and over, by selected demographic characteristics, 2019.
- <sup>47</sup> <u>https://www.health.act.gov.au/about-our-health-system/data-and-publications/healthstats/statistics-and-indicators/leading-causes</u>. The website states that "Burden of disease analysis is a technique that is used as a measure of population health. It is used to compare the impact of different diseases, conditions, injuries and risk factors on a population. This impact is a combination of the fatal (years of life lost due to premature death, YLL) and non-fatal (years lived in ill health or with disability, YLD) burden, they are then combined into a summary measure of health called disability-adjusted life years, or DALY. A DALY combines the impact of dying early and living with illness."
- <sup>48</sup> <u>https://health.act.gov.au/about-our-health-system/data-and-publications/healthstats/focus-health-topics</u>.
- <sup>49</sup> <u>https://www.health.act.gov.au/sites/default/files/2018-09/Canberra Hospital & Health Services</u> <u>COPD Patient Information Booklet\_.pdf.</u>
- <sup>50</sup> 4<sup>th</sup> Atlas of Variation see note 44 at pages 69-85.
- <sup>51</sup> For full information, please see: Falster M and Jorm L. *A guide to the potentially preventable hospitalisations indicator in Australia*. Centre for Big Data Research in Health, University of New South Wales in consultation with Australian Commission on Safety and Quality in Health Care

and Australian Institute of Health and Welfare; Sydney 2017. (Preventable hospitalisation Indicator Guide 2017) Available at:

https://www.safetyandquality.gov.au/sites/default/files/migrated/A-guide-to-the-potentiallypreventable-hospitalisations-indicator-in-Australia.docx

- <sup>52</sup> Preventable hospitalisation Indicator Guide 2017 at note 51: at page 3.
- <sup>53</sup> COPD-X Plan 2021 see note 8: at page 11.
- <sup>54</sup> Andrews J. Guyatt G. Oxman AD. Alderson P. et al. GRADE guidelines: 14. Going from evidence to recommendations: the significance and presentation of recommendations. 2013 *Journal of Clinical Epidemiology*, volume 66, pages 719-25.
- <sup>55</sup> <u>https://www.nps.org.au/professionals/chronic-obstructive-pulmonary-disease-copd.</u>
- <sup>56</sup> <u>https://www.nps.org.au/consumers/chronic-obstructive-pulmonary-disease-copd-explained.</u>
- <sup>57</sup> COPD-X Plan 2021 see note 8: at page 28.
- <sup>58</sup> ACT Auditor-General's Report Management of care for people living with serious and continuing illness. Report No. 7/2020.
- <sup>59</sup> Canberra Hospital and Health Services Operational Guideline. *Pulmonary Rehabilitation Program* (*Adult*) CHHS18/039, issues 13/02/2018, review date 01/02/2022.
- <sup>60</sup> Information and bookings can be found at <u>https://www.canberra.edu.au/health-clinics/clinics-on-offer/exercise-physiology</u>.
- <sup>61</sup> For further details, please contact CIT Fit & Well on (02) 6207 4309.
- <sup>62</sup> Maintaining Movement Videos are located here: <u>https://lungfoundation.com.au/resources/?user\_category=31&resource\_type=236&search=maint\_aining%20Movement</u>.
- <sup>63</sup> The Hughes Community Centre is located at Wisdom St, Hughes in the ACT. Phone contact: 02 6282 3777 and email: <u>contact@cotaact.org.au</u>.
- <sup>64</sup> The Groups newsletter for the past decade can be located at <u>https://www.creationcorporation.com.au/Clients/Lung%20Life%20Support%20Group%20Newslett</u> <u>ers/index.htm.</u> The group meets monthly at Weston Creek Labour Club Teesdale Cl, Stirling ACT 2902, Australia and have social events as well.
- <sup>65</sup> Contact this group through <u>https://www.sleepapnea-act.org.au/</u>.
- <sup>66</sup> 4<sup>th</sup> Atlas of Variation: see note 44 at pages 72, 75, Figure 2.8 at page 83 and Figure 2.6 at page 81.
- <sup>67</sup> 4<sup>th</sup> Atlas of Variation: see note 44 at page 80.
- <sup>68</sup> 4<sup>th</sup> Atlas of Variation: see note 44 at page 73.
- <sup>69</sup> Minister for Health and Aged Care. Universal Telehealth extended through 2021. Media Release 26 April 2021, where the Minister announced \$114M to extend current Telehealth arrangements, which cover most primary care services, as part of the 2021-2022 Budget.
- <sup>70</sup> Department of Health. COVID-19 Telehealth Services MBS changes Consumer Factsheet. MBS Online Last updated 17 March 2021: pages 1-5 at page 1. The list of service providers included in the Telehealth arrangements are listed on page 2. Available at: www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Factsheet-TempBB.
- <sup>71</sup> COPD-X Plan 2021 see note 8: at page 145, Boxes 12 and 13, and pages 145-146, Section X3, especially X3.1 and X3.2.
- ACT Auditor-General. ACT Auditor-General's Report on the Management of Care for People Living with Serious and Continuing Illness. <u>https://www.audit.act.gov.au/\_\_data/assets/pdf\_file/0007/1626037/Report-No.7-of-2020-</u> Management-of-care-for-people-living-with-serious-and-continuing-illness.pdf
- <sup>73</sup> Matheson MC. Abeysena C. Raven JM et al. How have we been managing chronic obstructive pulmonary diseases in Australia? 2006 *Internal Medicine Journal*, pages 92-99. https://doi:10.1111/j.1445-5994.2006.01011.x :page 92

- <sup>74</sup> Voelkel NF. Rising awareness of COPD in Primary Care. 2000 *Chest,* volume 117, pages 373S-375S: at page 372S.
- <sup>75</sup> Access Economics. *Economic impact of COPD and cost effective.* Report by Access Economics Pty Ltd for the Australian Lung Foundation.16 October 2008 (Access Economics Report 2008): Chapter 6, pages 48-57.
- <sup>76</sup> Access Economics Report 2008 see note 75: at page 48.
- <sup>77</sup> <u>https://lungfoundation.com.au/resources/copd-case-finding-results-form-general-practice/.</u>
- <sup>78</sup> https://lungfoundation.com.au/resources/copd-case-finding-results-form-community-pharmacy/.
- <sup>79</sup> The main position paper by Lung Foundation Australia on Case finding is <u>https://lungfoundation.com.au/resources/copd-case-finding-position-paper/.</u> See also the Primary Care Respiratory Toolkit at <u>https://lungfoundation.com.au/primary-care-respiratory-toolkit/</u>. A Checklist for consumers is also available at: <u>http://www.lungfoundation.com.au/lungaware09/lung-health-checklist?view=onepage&catid=3</u>.
- <sup>80</sup> Lung Foundation Australia. The Australian Lung Foundation Position Paper on the use of COPD screening devices for targeted COPD case finding in community settings. 2011. Available at: <a href="https://copdx.org.au/wp-content/uploads/2012/03/lungfoundation.com.au\_wp-content\_uploads\_2014\_02\_Position-Paper.pdf">https://copdx.org.au/wp-content/uploads/2012/03/lungfoundation.com.au\_wp-content\_uploads\_2014\_02\_Position-Paper.pdf</a>.
- <sup>81</sup> This may because of other conditions that can either give false spirometry results or where the breath effort required may impact on recent other conditions: <u>https://www.medscape.com/answers/303239-77798/what-are-contraindications-to-spirometry-inpulmonary-function-testing</u>.
- <sup>82</sup> <u>https://lungfoundation.com.au/health-professionals/conditions/copd/diagnosis/</u> under What is a COPD screening device?
- <sup>83</sup> <u>https://lungfoundation.com.au/resources/copd-screening-with-the-piko-6-device/.</u>
- <sup>84</sup> https://lungfoundation.com.au/resources/copd-screening-with-the-copd-6-device/.
- <sup>85</sup> Information on carrying out and interpreting spirometry is available in a number of ways: eg the Capital Health Networks on-line training, the Lung Foundation Australia's primary care respiratory tool kit. <u>https://lungfoundation.com.au/primary-care-respiratory-toolkit/:</u> the National Asthma Council's Spirometry training <u>https://www.nationalasthma.org.au/health-professionals/educationtraining/spirometry-training</u> as well as specific training through Health Department's in other jurisdictions eg NSW Health training on virtual respiratory assessment processes in COVID-19. <u>https://www.health.nsw.gov.au/Infectious/covid-19/communities-of-practice/Pages/guide-virtualresp-assessment.aspx</u>.
- <sup>86</sup> COPD-X Plan 2021 see note 8: at page 27.
- <sup>87</sup> COPD-X Plan 2021 see note 8: at page 30, Box 4.
- <sup>88</sup> COPD-X Plan 2021 see note 8: at pages 28-29.
- <sup>89</sup> US Preventive Services Task Force (USPSTF) *Screening for Chronic Obstructive Pulmonary Disease.* USPSTF Recommendation Statement, reproduced in 2016 *Journal of the American Medical Association* (JAMA) volume 315, Issue 13, pages 1372-1377: at page 1372.
- <sup>90</sup> Spyratos D. Haidich AB. Chloros D. et al. Comparison of Three Screening Questionnaires for Chronic Obstructive Pulmonary Disease in the Primary Care. 2017 *Respiration*, volume 93, pages 83-89 at page 88. <u>https://www.karger.com/Article/FullText/453586</u>.
- <sup>91</sup> See,eg, van Boven JFM. Costs of case-finding uncovered: time to revisit COPD's value pyramid. 2019. *Thorax – BMJ Journals*. 2019 volume74, issue 8: <u>http://dx.doi.org/10.1136/thoraxjnl-2019-213440</u>.
- <sup>92</sup> Lambe T. Adab P. Jordan RE. et al Model-based evaluation of the long term cost effectiveness of systematic case finding for COPD in primary care. 2019 *Thorax – BMJ Journals*. Volume 74, issue 8: <u>http://dx.doi.org/10.1136/thoraxjnl-2018-212148</u>.
- <sup>93</sup> MBS Analytics. Medicare year to date dashboard GP Non-Referred attendances, 2020-21 Jul-Dec YTD. Available at: <u>https://www1.health.gov.au/internet/main/publishing.nsf/Content/Medicare%20Statistics-1</u>.

- 94 Boddy N. Canberrans wait on average more than 6 days to see their preferred doctor. Canberra Times. 21 November 2014: https://www.canberratimes.com.au/story/6075563/canberrans-waiton-average-more-than-6-days-to-see-their-preferred-doctor/digital-subscription/. While this article is dated, the researcher was unable to uncover more recent data on waiting times in the ACT. Anecdotally and experientially, these continue to be very varied – from days to weeks.
- 95 For example, the median length of consultation is the last BEACH (Bettering the Evaluation and Care of Health) study on general practice in Australia published in 2014-15 was 13.0 minutes. Britt H. Miller GC. Henderson J. et al General practice activity in Australia 2014-15. General practice series no. 38. 2015 Sydney University Press, Sydney. Available at for purchase at https://sydneyuniversitypress.com.au/products/84670; download found at https://www.sydney.edu.au/medicine-health/our-research/research-centres/bettering-theevaluation-and-care-of-health/publication.html: at page 41.
- 96 The following data was obtained from Services Australia on 16 June 2021.

Item number			Total	%
	ACT	%		
	Services	of total	Services	of total
23 - Consult B < 20mins	1,306,657	80%	89,952,840	79%
3 - Consult A short	41,257	3%	4,212,466	4%
36 - Consult C >20 <40 mins	261,562	16%	18,267,715	16%
44 - Consult D >40 mins	24,307	1%	1,656,326	1%
Total	1,633,783		114,089,347	

#### Medicare data July 2019-June 2020 ACT only and Total

#### Disclaimer

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Medicare Australia recommends that users exercise their own care, skill and diligence with respect to the use and interpretation of the information and data.

The 83% estimate counted Consultations under item 3 and 23 in the 83% figure.

- 97 Spiller S. Survey Results: Looking after your health with a long-term condition. 18 December 2020 Health Care Consumers Research Report: see pages 27-28 Interacting with health professionals. This research project included people with COPD (11%), but covered consumers with a wide range of other conditions as well.
- 98 Australian Medicare Local Alliance. 2012 General Practice Nurse National Survey Report.
- 99 Heywood T. Laurence C. The general practice nurse workforce – estimating future supply. 2018 Australian Journal of General Practice, volume 47, issue 11, November 2018, pages 788-795. See pages 788 and 789.
- <sup>100</sup> COPD-X Plan 2021 see note 8: at page 29.
- 101 COPD-X Plan 2021 - see note 8: at page 28.
- 102 See study undertaken between Lung Foundation Australia and community pharmacies COPD Risk Assessment and Screening in Community Pharmacy https://youtu.be/Fg8PdnW1alk, which led to Lung Foundation Australia producing an on-line course for COPD community screening for pharmacists: see https://lungfoundation.com.au/events/copd-pharmacy-online-training/.
- 103 See, eg, https://www.findapharmacy.com.au/our-services/copd-assessment-and-management, which shows 16 pharmacies offering this service in the ACT.
- 104 Laing J. Abramson MJ. Zwar NA et al. Diagnosing COPD and supporting smoking cessation in general practice: evidence - practice gaps . 2018 Medical Journal of Australia, 15 January 2018, volume 208, issue 1, pages 31-34: at page 31.
- 105 Chalton M. Diemert L. Cohen JE. et al Estimating the number of guit attempts it takes to guit smoking successfully in a longitudinal cohort of smokers. 2016 BMJ Open volume 6, e011045. doi:10.1136/bmjopen-2016-011045: at page 5 Discussion. Available at: http://dx.doi.org/10.1136/bmjopen-2016-011045) See also Greenhalgh, EM., Jenkins, S, Stillman, S., & Ford, C. 7.2 Quitting activity. In Greenhalgh, EM, Scollo, MM and Winstanley, MH [editors]. Tobacco in Australia: Facts and issues. Cancer Council Victoria 2020 Melbourne. Available from http://www.tobaccoinaustralia.org.au/chapter-7-cessation/7-2-quitting-activity. November 2021

- <sup>106</sup> Yang IA. Dabscheck EJ. George J et al. COPD-X Concise Guide. Lung Foundation Australia 2019 Brisbane. (Concise COPD-X 2019): available at https://lungfoundation.com.au/resources/copd-x-concise-guide/ : Table 2 – page 14.
- <sup>107</sup> COPD-X Plan 2021 see note 8: at page 36.
- <sup>108</sup> COPD-X Plan 2021 see note 8: at pages 36-37.
- <sup>109</sup> Lorig K. Sobe D. Laurent D et al. Living a healthy life with chronic conditions self-management skills for heart disease, arthritis, diabetes, depression, asthma, bronchitis, emphysema and other physical and mental health conditions. 5th edition. 2020 Bull Publishing Company, Colorado. Kindle copy: see Chapter 1 at location 260.
- <sup>110</sup> COPD-X Plan 2021 see note 8: at page 32, Box 6 and section C5.1
- <sup>111</sup> COPD-X Plan 2021 see note 8: at pages 33-35.
- <sup>112</sup> COPD-X Plan 2021 see note 8: at pages 38-59.
- <sup>113</sup> COPD-X Plan 2021 see note 8: at page 60.
- <sup>114</sup> COPD-X Plan 2021 see note 8: at page 60.
- <sup>115</sup> COPD-X Plan 2021 see note 8: at pages 60-61.
- <sup>116</sup> <u>https://lungfoundation.com.au/patients-carers/support-services/lung-disease-and-exercise/pulmonary-rehabilitation/.</u>
- <sup>117</sup> Lung Foundation Australia. Pulmonary Rehabilitation Toolkit. Accessed at <u>https://pulmonaryrehab.com.au/</u> on 20 July 2021.
- <sup>118</sup> Lung Foundation Australia. Importance of Education. Accessed at https://pulmonaryrehab.com.au/importance-of-education/ on 20 July 2021.
- <sup>119</sup> See, eg, <u>https://lungfoundation.com.au/resources/pulmonary-rehabilitation-a-patients-point-of-view/</u>.
- <sup>120</sup> Additional video information and instructions on YouTube, can be looked at by searching on Pulmonary Rehabilitation. Those which have been produced by various hospitals or health trusts in the United Kingdom National Health Service are similar to the models used in Australia and the ACT eg Pulmonary rehabilitation for COPD after an exacerbation by Royal Brompton and Harefield Hospital 2018 <u>https://www.youtube.com/watch?v=jNtNPsC9311</u> accessed 20 July 2021, which provides an outline of patient experiences and what to expect (less than 5 mins). There are also some 20 min programs, like the NHS Forth Valley, which consumers can do along with others in their own home. <u>https://www.youtube.com/watch?v=j9Og5r0W6rQ</u>.
- <sup>121</sup> For more information about the ACT Obesity Management Service, see <u>https://health.act.gov.au/services-and-programs/chronic-disease-management/obesity-management-service</u>.
- <sup>122</sup> British Lung Foundation. What happens if I'm not active? <u>https://www.blf.org.uk/support-for-you/keep-active/how-will-it-affect-my-breathing</u> Viewed 20 July 2021.
- <sup>123</sup> British Lung Foundation. How can being active help my breathing? <u>https://www.blf.org.uk/support-for-you/keep-active/how-will-it-affect-my-breathing</u> Viewed 20 July 2021.
- <sup>124</sup> COPD-X Plan 2021 see note 8. See Section 06.5 Physical activity and sedentary behaviour, pages 64-66 and Appendix 4 for some everyday hints to reduce sedentary time.
- <sup>125</sup> Cheng SWM. McKeough Z. Alison J et al. Associations of total and type-specific physical activity with mortality in chronic obstructive pulmonary disease: a population-based cohort study. 2018 *BioMed Central Public Health* volume 18, article 268: found at https://bmcpublichealth.biomedcentral.com/articles/10.1186/s12889-018-5167-5.
- <sup>126</sup> <u>https://lungfoundation.com.au/patients-carers/support-services/lung-disease-and-exercise/lungs-in-action/</u>.
- <sup>127</sup> There are videos available on the Lung Foundation Australia website, including the Maintaining Movement Series, which includes exercising while watching television, in the kitchen or in the loungeroom. Other videos include stories of consumer experiences eg Lungs in Action: A patient's point of view and Webinars that teach about exercising safely with different conditions.
All of these can be found at: <u>https://lungfoundation.com.au/patients-carers/support-services/lung-disease-and-exercise/</u>. Other resources include Better Health Channel – Victorian Government. Breathing Problems and Exercise, https://www.betterb.actb.vic.gov.ov/bealtb./bealtbuliving/breathing.problems.org

https://www.betterhealth.vic.gov.au/health/healthyliving/breathing-problems-andexercise#specific-breathing-exercises.

- <sup>128</sup> See, eg Lung Foundation Australia. Better Living with Exercise your personal guide. Downloadable at <u>https://lungfoundation.com.au/resources/better-living-with-exercise-booklet/</u>; another source is a special weekly newsletter from the medically reviewed Heathline Website – with one on COPD and exercises <u>https://www.healthline.com/health/copd/exercise</u>. See also exercises in Lorig et al 2003 at note 109.
- <sup>129</sup> COPD-X Plan 2021 see note 8: at pages 69-73.
- <sup>130</sup> COPD-X Plan 2021 see note 8: at page 73, Box 7.
- <sup>131</sup> COPD-X Plan 2021 see note 8: at pages 74-99.
- <sup>132</sup> COPD-X Plan 2021 see note 8: There are detailed guidelines under P1.1 on Smoking cessation on pages 100-106.
- <sup>133</sup> COPD-X Plan 2021 see note 8: at page 111.
- <sup>134</sup> COPD-X Plan 2021 see note 8: at page 111.
- <sup>135</sup> Thoracic Society of Australia and New Zealand. Adult Domiciliary Oxygen Therapy Clinical Practice Guideline. March 2014 : <u>https://www.thoracic.org.au/journal-publishing/command/download\_file/id/33/filename/TSANZ-DomiciliaryOxygen-Guidelines-2016-web.pdf</u>. Part of this document was also published in 2016 as McDonald CF. Whyte K. Jenkins S. Serginson J. Frith P. Clinical Practice Guideline on Adult Domiciliary Oxygen Therapy: Executive summary from the Thoracic Society of Australia and New Zealand. Respirology, volume 21: pages 76–78 at <u>https://doi.org/10.1111/resp.12678</u> which notes it was first published on 24 November 2015. (TSANZ CPG 2015).
- <sup>136</sup> Low blood oxygen levels cause "hypoxemic respiratory failure." High carbon dioxide cause "hypercapnic respiratory failure". These can arise from a number of conditions as well as COPD, and can be life-threatening if untreated. Kahn A. Chronic Respiratory failure. 30 March 2018. Sighted at Healthline website on 24 July, 2021. See: <u>https://www.healthline.com/health/chronicrespiratory-failure#symptoms.</u>
- <sup>137</sup> For a detailed explanation of this effect, see <u>https://www.youtube.com/watch?v=YS17o0VC-14</u>. See also Sarker M. Niranjan N. Banyal PK. Mechanisms of hypoxemia. *Lung India*. 2017 January-February, volume 34, issue 1, pages 47-60. Available at: <u>https://www.ncbi.nlm.nih.gov/pmc/articles/PMC5234199/</u>.
- <sup>138</sup> In the context of wider use of pulse oximetry outside the hospital setting, when people were monitoring their health at home where they had COVID-19, the US Food and Drug Administration issued a Safety Communication about situations where pulse oximeters may be less accurate, including where someone has dark skin pigmentation on 19 February 2021. A copy of this advice can be found at <u>https://www.fda.gov/medical-devices/safety-communications/pulse-oximeteraccuracy-and-limitations-fda-safety-communication.</u>
- <sup>139</sup> Beasley R. Chien J. Douglas J. et al Target oxygen saturation range: 92-96% versus 94-98. *Respirology* 2017 January, volume 22, issue 1, pages 200-202. doi: 10.1111/resp.12879.
- <sup>140</sup> Beasley R. Chien J. Douglas J. et al Thoracic Society of Australia and New Zealand oxygen guidelines for acute oxygen use in adults: 'Swimming between the flags". *Respirology* 2015, volume 20, pages 1182-1191: at page 1184, Table 2, recommendations 5 and 6.
- <sup>141</sup> Beasley R. Chien J. Douglas J. et al Thoracic Society of Australia and New Zealand oxygen guidelines for acute oxygen use in adults: 'Swimming between the flags". *Respirology* 2015, volume 20, pages 1182-1191. Table 2, Key Recommendation2 sets out when Arterial Blood Gas testing should occur in the acute setting.
- <sup>142</sup> For more information about understanding arterial blood gas results, see Verma AK. Roach P. The interpretation of arterial blood gases. *Australian Prescriber*. 2010, volume 33, pages 124-129: found at <u>https://www.nps.org.au/australian-prescriber/articles/the-interpretation-of-arterialblood-gases</u>.

- <sup>144</sup> Brill SE. Wedzicha JA. Oxygen therapy in acute exacerbations of chronic obstructive pulmonary disease. *International Journal of COPD,* volume 9, pages 1241-252.
- <sup>145</sup> COPD-X Plan 2021 see note 8: at page 111.
- <sup>146</sup> TSANZ CPG 2015, see note 135 at pages 76-77.
- <sup>147</sup> COPD-X Plan 2021 see note 8: at page 112-114.
- <sup>148</sup> COPD-X Plan 2021 see note 8: at page 114-115.
- <sup>149</sup> National Voices presentation 2013. Available at : <u>https://www.england.nhs.uk/wp-content/uploads/2013/05/nv-narrative-cc.pdf</u>.
- <sup>150</sup> For example, for doctors and consumers to complete together and discuss there are: My COPD Action Plan <u>https://lungfoundation.com.au/resources/copd-action-plan/</u> and my COPD Checklist <u>https://lungfoundation.com.au/resources/my-copd-checklist/</u>. For doctors and health professionals there are useful care planning resources, such as: Stepwise Management of Stable COPD <u>https://lungfoundation.com.au/resources/stepwise-management-of-stable-copd/</u>; and the General Practice Management Plan/Team care arrangements template: <u>https://lungfoundation.com.au/resources/gp-management-plan-team-care-arrangement-template/</u>.
- <sup>151</sup> Medicare item numbers relating to Chronic disease management by general practitioners include 721, 723, 729, 731 and 732. <u>http://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&qt=ItemID&q=721</u>. For further details on these items, see Australian Government Department of Health. *Chronic Disease Management Provider Information*. Factsheet February 2014. Available at: <u>https://www1.health.gov.au/internet/main/publishing.nsf/Content/mbsprimarycare-factsheetchronicdisease.htm</u>.
- <sup>152</sup> MBS item 10997, which may be used for checks on clinical progress, monitoring medication compliance, self-management advice and the collection of information to support the GP or other medical practitioner reviews of Care Plans (up to 5 per calendar year). <u>http://www9.health.gov.au/mbs/fullDisplay.cfm?type=item&qt=ltemID&q=10997</u>.
- <sup>153</sup> See, eg, Medicare Item number 900; <u>http://www9.health.gov.au/mbs/fullDisplay.cfm?type=note&q=AN.0.52&qt=noteID&criteria=Medication%20Review</u>
- <sup>154</sup> See Coronavirus (COVID information) at <u>http://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Home sighted 31 July</u> <u>2021</u>.
- <sup>155</sup> Australian Government Department of Health. COVID-19 Temporary MBS Telehealth Services. MBS changes factsheet. 17 March 2021. <u>https://www.mbsonline.gov.au/internet/mbsonline/publishing.nsf/Content/Factsheet-TempBB</u>.
- <sup>156</sup> COPD-X Plan 2021 see note 8: at pages 145-146 (Section X3, especially 3.1 and 3.2).
- <sup>157</sup> COPD-X Plan 2021 see note 8: at page 145, Boxes 12 and 13.
- <sup>158</sup> COPD-X Plan 2021 see note 8: at page 149, section X3.6.
- <sup>159</sup> The Canberra Lung Life Support Group meets monthly at the Labor Club at Weston. Details of their activities are available in their newsletters which can be found at <u>https://www.creationcorporation.com.au/Clients/Lung%20Life%20Support%20Group%20Newslett</u> <u>ers/index.htm</u>.
- <sup>160</sup> Copies of this Report are available at <u>https://www.pc.gov.au/research/completed/chronic-care-innovations</u>. As well as the Report, the Productivity Commission has recorded a webinar on its work and made it available on YouTube <u>https://www.youtube.com/watch?v=Ed2upjV7vsY.</u>
- <sup>161</sup> https://www.thoracic.org.au/about-us/special-interest-groups.
- <sup>162</sup> Download the Framework from here: <u>https://www.thoracic.org.au/journal-</u> publishing/command/download\_file/id/42/filename/2016\_KSF\_final\_with\_Section\_\_logo.pdf.
- <sup>163</sup> <u>https://lungfoundation.com.au/health-professionals/networks/copd-nurse-network/.</u>
- <sup>164</sup> <u>https://lungfoundation.com.au/events/copd-nurse-online-training/</u>.
- <sup>165</sup> <u>https://www.acn.edu.au/education/cpd-online/respiratory-nursing.</u>

- <sup>166</sup> <u>https://lungfoundation.com.au/health-professionals/networks/copd-nurse-network/</u>.
- <sup>167</sup> <u>https://www.thoracic.org.au/about-us/special-interest-groups</u>.
- <sup>168</sup> The University offers Postgraduate qualifications in chronic disease management <u>https://www.flinders.edu.au/study/courses/postgraduate-chronic-condition-management</u>, as well as a short course, designed and relevant for allied health practitioners, aged care workers, nurses, GPs and Aboriginal health practitioners, and done on-line through modules: <u>https://www.flinders.edu.au/engage/community/short-courses/chronic-condition-managementprogram</u>.
- <sup>169</sup> COPD-X Plan 2021 see note 8: at pages 124-133.
- <sup>170</sup> COPD-X Plan 2021 see note 8: at page125, last paragraph.
- <sup>171</sup> Lorig et al 2003 at note 109: Under section what is self-management?
- <sup>172</sup> Australian Government Productivity Commission. *Innovation in care for chronic health conditions. Productivity Reform Case Study* March 2021 Commonwealth of Australia 2021 Canberra. (Productivity Commission Innovations Report 2021) Available at: https://www.pc.gov.au/research/completed/chronic-care-innovations: see page 43.
- <sup>173</sup> Productivity Commission Innovations Report 2021- see note 172, page 44.
- <sup>174</sup> Appointments can be made through <u>https://lungfoundation.com.au/patients-carers/support-</u> services/support/.
- <sup>175</sup> <u>https://lungfoundation.com.au/patients-carers/support-services/support/</u>.
- <sup>176</sup> The series is available through <u>https://youtube.com/playlist?list=PLx5RMZtuxzUS6XD6r-jf6kcB5X2vRf6Uc</u>.
- <sup>177</sup> Lung Foundation Australia materials on COVID are at <u>https://lungfoundation.com.au/lung-health/protecting-your-lungs/coronavirus-disease-covid-19/what-you-need-to-know/</u> For those whose mental health is being impacted, there are additional materials at <u>https://lungfoundation.com.au/news/mental-impact-of-covid-19/</u>.
- <sup>178</sup> <u>https://www.youtube.com/watch?v=abJ\_bCC16IE</u>.
- <sup>179</sup> <u>https://lungfoundation.com.au/blog/</u>.
- <sup>180</sup> Polak Scowcroft Thesis 2013 at note 3.
- <sup>181</sup> Some of the exercise class and physical activity resources which are available in the ACT are discussed earlier in the report at page 29.
- <sup>182</sup> See, eg, Telstra's Tech Savvy Seniors program which includes on-line <u>https://www.telstra.com.au/tech-savvy-seniors</u> and a video <u>https://youtu.be/ge-I3080liY</u>; Canberra Seniors offers weekly computer classes – to find out more details, contact <u>cseniors@bigpond.com</u>.
- <sup>183</sup> Peacock JL. Anderson HR et al Outdoor air pollution and respiratory health in patients with COPD. *Thorax* 2011, volume 66, pages 591-596.Cited at COPD-X Plan 2021 - see note 8: at page136.
- <sup>184</sup> COPD-X Plan 2021 see note 8: at page 134.
- <sup>185</sup> COPD-X Plan 2021 see note 8: Box 11 at pages 138-139.
- <sup>186</sup> COPD-X Plan 2021 see note 8: at page 153. Copies of this can be downloaded from: <u>https://lungfoundation.com.au/resources/managing-copd-exacerbation-checklist/</u>.
- <sup>187</sup> In the previous ACT Community Health Centres model which existed up to the 1980s and in Aboriginal-Controlled Health Services models (like Winnunga Nimmityjah), some parts of the Canberra community have experienced more integrated and coordinated care at different times often under different funding arrangements than exist currently. The Winnunga model remains as an outstanding example of health delivery through integrated health and social care.
- <sup>188</sup> See eg, examples listed on <u>https://www.england.nhs.uk/integrated-care-pioneers/resources/patient-care/</u> and the principles more generally at https://www.england.nhs.uk/integrated-care-pioneers/.

- <sup>189</sup> Macklin J. assisted by Willcox S. McClelland A. *The National Health Strategy. Setting the Agenda for Change.* Background Paper No 1. November 1990: pages 14-17.
- <sup>190</sup> Dr Sidney Sax was head of the Commonwealth Government's Hospitals and Health Services Commission between 1972-1978 and a leader in public health and health reform: <u>https://www.saxinstitute.org.au/about-us/our-history/</u>.
- <sup>191</sup> National Health Strategy. *The Australian Health Jigsaw- Integration of Health Care Delivery*. National Health Strategy Issues Paper No 1. July 1991. Director -Ms Jenny Macklin: page 11. It is also worth looking at the Executive Summary of this Issues Paper – pages 6-10.
- <sup>192</sup> Centre for Health Advancement and KPMG Management Consulting. The Australian Coordinated Care Trials – Interim Technical National Evaluation Report. Appendices 21 May 1999: Commonwealth of Australia 1999 Canberra: page 6.
- <sup>193</sup> Reference is identical to note 192.
- <sup>194</sup> Marcus D. Coordinating Care in an uncoordinated health system: the development and implementation of coordinated care trials in Australia. Current Issues Brief 11 1998-99. Commonwealth Parliamentary Library Social Policy Group. A Senate Standing Committee on Community Affairs Report entitled *Healing our Hospitals: A report on public hospital funding*. December 2000 provides a useful summary of the coordinated care trials in Chapter 4 <u>https://www.aph.gov.au/Parliamentary\_Business/Committees/Senate/Community\_Affairs/Comple ted\_inquiries/1999-02/pubhosp/report/index (Healing our Hospitals 2000).</u>
- <sup>195</sup> Healing our hospitals 2000, see note 194. Pages 45-49, especially paragraph 4.10 on page 48 and Table 4.2 on page 49.
- <sup>196</sup> Price Waterhouse Coopers. The National Evaluation of the Second Round of Coordinated Care Trials – Final Report. Coordination of Care and efficiency of Healthcare: Lessons from the Second Round of Australian Coordinated Care Trials. 2007 Australian Government, Department of Health and Aging, Canberra: Volume 3, Appendix C The first round of Coordinated Care Trials: aims and results- pages 16-17. Available at <u>https://apo.org.au/sites/default/files/resourcefiles/2008-04/apo-nid8664.pdf</u> (Round 2 Coordinated Care Trial Evaluation 2007).
- <sup>197</sup> Healing our hospitals 2000, see note 194. Pages 49-50.
- <sup>198</sup> Office for Aboriginal and Torres Strait Islander Health (OATSHI). *The Aboriginal and Torres Strait Islander Coordinated Care Trials National Evaluation Report. Volume1. Main Report.* Prepared by KPMG Consulting. Commonwealth of Australia 2001 Canberra (OATSHI Report 2001): page 17.
- <sup>199</sup> OATSHI Report 2001 at note 198 page 16.
- <sup>200</sup> OATSHI Report 2001 at note 198 page 19.
- <sup>201</sup> Sllagy C. KPMG, Church , Esterman A. Pradham M. *The Australian Coordinated Care Trials Interim Technical National Evaluation Report Appendices*. Prepared by Centre for Health Advancement and KPMG Management Consulting 21 May 1999. Commonwealth of Australia 1999 Canberra. Chapter 4 the Model of Care Coordination, ages 11-19, especially at pages11-12.
- <sup>202</sup> OATSHI Report 2001 at note 198 pages 25-26.
- <sup>203</sup> Round 2 Coordinated Care Trial Evaluation 2007 see note 196: Volume 3, Appendix C, pages 16-19.
- <sup>204</sup> Healing our hospitals 2000, see note 194- page 50.
- <sup>205</sup> Round 2 Coordinated Care Trial Evaluation 2007 see note 203, Part 1, page 8.
- <sup>206</sup> Round 2 Coordinated Care Trial Evaluation 2007 see note 203, Part 1, page 8. See also pages 9-33, for the Findings.
- <sup>207</sup> Round 2 Coordinated Care Trial Evaluation 2007 see note 203, Part 1, page 14 and Key finding 9, page 29. A detailed examination of all the findings of that evaluation should also inform any new developments.
- <sup>208</sup> De Boer R, Boxall AM, Buckmaster L. et al. The interim report of the National Health and Hospitals Reform Commission - a summary and analysis. Parliamentary Library Research Paper 24 2008-09, Social Policy Section 2009 – available at

https://www.aph.gov.au/About\_Parliament/Parliamentary\_Departments/Parliamentary\_Library/pu bs/rp/rp0809/09rp24.

- <sup>209</sup> National Health and Hospital Reform Commission. 27 July 2009. Commonwealth of Australia 2009 Canberra. Available at: <u>https://apo.org.au/node/17921</u>.
- <sup>210</sup> Commonwealth Department of Health. The national health reform agenda implications for CVD. April 2011. <u>https://www1.health.gov.au/internet/publications/publishing.nsf/Content/cardio-pubs-revresp-toc~cardio-pubs-revresp-nat.</u>
- <sup>211</sup> See, eg, Australian Senate. Finance and Public Administration References Committee. Implementation of the National Health Reform Agreement. Commonwealth of Australia 2013, Canberra. <u>https://www.aph.gov.au/Parliamentary\_Business/Committees/Senate/Finance\_and\_Public\_Administration/Completed%20inguiries/2010-13/publichospitalfunding/report/index</u>
- <sup>212</sup> Australian Government Department of Health and Ageing. Building a 21<sup>st</sup> Century Primary Health Care System – Australia's First National Primary Health Care Strategy. Commonwealth of Australia 2010 Canberra. (Primary Health Care Strategy 2010) Available at https://extranet.who.int/nutrition/gina/en/node/23610: page 31.
- <sup>213</sup> Primary Health Care Strategy 2010 see note 212, page 32.
- Standing Council on Health. National Primary Health Care Strategic Framework. April 2013. Commonwealth of Australia 2013 Canberra. (Primary Care Framework 2013) Available at: <u>https://www1.health.gov.au/internet/main/publishing.nsf/Content/nphc-strategic-framework</u>: page 5.
- <sup>215</sup> Primary Care Framework 2013 at note 214, page 12.
- <sup>216</sup> Primary Care Framework 2013 at note 214, page 14-15.
- <sup>217</sup> Winners and Losers of the 2014 Budget <u>https://www.abc.net.au/news/2014-05-13/budget-winners-and-losers/5433178?nw=0</u>. See also Then and now: the Abbott government's broken promises. Sydney Morning Herald, 14 May 2014 2.32pm <u>https://www.smh.com.au/national/then-and-now-the-abbott-governments-broken-promises-20140514-zrcfr.html</u>.
- <sup>218</sup> See, eg. Wagner H. Coleman K. Reid R, Phillips K and Sugarman J. Guiding Transformation: How medical Practices can become Patient-Centred Medical Homes. February 2012. Commonwealth Fund 2012 New York. Available at: <u>http://www.commonwealthfund.org/Publications/Fund-Reports/2012/Feb/Guiding-Transformation.aspx</u>. See also: Bodenheimer T. Ghorob A. Willard-Grace R. Grumbach K. The 10 building blocks of high-performing primary care. 2014 *Annals of Family Medicine*. March/April 2014, volume 12, issue 2, pages 166-171 doi:10.1370/afm.1616.
- <sup>219</sup> See, for example, the pioneering work of Dr Tony Lembke though his website the Australian Centre for the Medical Home, <u>http://medicalhome.org.au/</u>. See in particular his page called "The Person Centred Heath System and the Medical Home" <u>http://medicalhome.org.au/the-personcentred-health-system-and-the-medical-home/</u>. It is a very useful website.
- <sup>220</sup> The United Kingdom (UK) uses a change strategy based around Integrated Care Pioneers. This program commenced in 2013. Its first Annual Report at <u>https://www.england.nhs.uk/integrated-care-pioneers/resources/</u> provides details of how it was set up. In March 2021, the NHS achieved its commitment to implement integrated care systems across England. <u>https://www.england.nhs.uk/2021/03/nhs-achieves-key-long-term-plan-commitment-to-roll-out-integrated-care-systems-across-england/</u> The United Kingdom version of Primary Care Home is described here: <u>https://www.england.nhs.uk/new-care-models/pch/</u>.
- <sup>221</sup> See Primary Health Care Advisory Group Overview: at <u>https://www1.health.gov.au/internet/main/publishing.nsf/Content/PrimaryHealthCareAdvisoryGroup-1#overview</u>.
- Primary Health Care Advisory Group. Better Outcomes for People with Chronic and Complex Health Conditions - Final Report. Commonwealth Department of Health 2015 Canberra. (Better Care Report 2015) Available at: <u>https://www1.health.gov.au/internet/main/publishing.nsf/Content/76B2BDC12AE54540CA257F72</u> 001102B9/\$File/Primary-Health-Care-Advisory-Group\_Final-Report.pdf.

- <sup>223</sup> See Media Releases all dated 31 March 2016. Ley S. Health Care Homes to keep chronically-ill out of hospital. Turnbull M. Ley S. A Healthier Medicare for Chronically III patients.
- <sup>224</sup> Better Health Care Report 2015 see note 222: page 2.
- <sup>225</sup> Australian Government Department of Health PHN Background: at <u>https://www1.health.gov.au/internet/main/publishing.nsf/Content/PHN-Background</u>.
- <sup>226</sup> Health Minister Ley S. Health Care Homes to keep chronically-ill out-of-hospital. Media Release 31 March 2016: page 2.
- <sup>227</sup> Better Health Care Report 2015 see note 222: page 4. This model aligns with the 10 building blocks of high-performing primary care underpinning the patient centred medical home model formulated under the Commonwealth Fund Report of 2012, at note 218 above.
- <sup>228</sup> The home page for the Navigating the Healthcare Neighbourhood can be found here: <u>https://aci.health.nsw.gov.au/nhn</u>.
- <sup>229</sup> The diagram is found on <u>https://www.aci.health.nsw.gov.au/nhn/patient-centred-medical-home-model/what-is-the-patient-centred-medical-home-model.</u>
- <sup>230</sup> The home page for the Navigating the Healthcare Neighbourhood can be found here: <u>https://aci.health.nsw.gov.au/nhn.</u>
- <sup>231</sup> The video is at the top of this page: <u>https://www.aci.health.nsw.gov.au/nhn/patient-centred-medical-home-model/what-is-the-patient-centred-medical-home-model.</u>
- <sup>232</sup> See eg Commonwealth Health Video called Health Care Homes Animation: <u>https://youtu.be/1hV7NBT0plY</u> and the NSW Agency for Clinical Innovation' <u>https://vimeo.com/194741474</u>. There are lots of other material on the NSW Agency for Clinical Innovation about health care homes and health care neighbourhoods more generally. <u>https://aci.health.nsw.gov.au/nhn</u>.
- <sup>233</sup> Health Care Homes program extended. Section on the following web-page: https://www1.health.gov.au/internet/main/publishing.nsf/Content/health-care-homes.
- <sup>234</sup> <u>https://www1.health.gov.au/internet/main/publishing.nsf/Content/Evaluation-of-the-Health-Care-Homes-Program</u>.
- <sup>235</sup> Health Policy Analysis. Evaluation of the Health Care Homes program- Interim Evaluation report 2020: Volume 1 – Summary Report. Australian Government Department of Health. 2000 Canberra. <u>https://www1.health.gov.au/internet/main/publishing.nsf/Content/Evaluation-of-the-Health-Care-Homes-Program</u> (HCH Interim Report 2020): page 4.
- <sup>236</sup> HCH Interim Report 2020 see note 235: pages 29-31.
- <sup>237</sup> For details of the October 2020 Report to develop new arrangements for National Cabinet and National Cabinet Reform Committees (which includes Health), see <u>https://www.pmc.gov.au/sites/default/files/final-report-review-coag-councils-ministerial-forums.pdf</u>. The structural relationships are set out in <u>https://www.pmc.gov.au/sites/default/files/federal-relations-architecture-diagram\_0.pdf</u>
- <sup>238</sup> Australian Institute of Health and Welfare. (AIHW) Aboriginal and Torres Strait Islander Health Performance Framework 2020 summary report. Cat. No. IHPF 2: Canberra 2020 AIHW. (AIHW Indigenous Health Performance 2020): at page 2. Available at <u>https://www.indigenoushpf.gov.au/</u>.
- <sup>239</sup> This is part of the Closing the Gap initiative. For further details on annual reports, see <u>https://www.indigenoushpf.gov.au/</u>.
- <sup>240</sup> AIHW Indigenous Health Performance 2020 see note 238: at page 3.
- <sup>241</sup> The proportion of Indigenous Australians aged 15 and over who smoked daily fell from 45% in 2008 to 37% in 2018–19. The proportion of Indigenous Australians aged 15–17 who smoked fell from 22% to 13% between 2008 and 2018–19 and the proportion who had never smoked increased from 72% to 85% over the same period. The proportion of Indigenous women who smoked during pregnancy fell from 54% in 2006 to 44% in 2017. AIHW Indigenous Health Performance 2020 see note 238: at page 11.
- <sup>242</sup> AIHW Indigenous Health Performance 2020 see note 238: at pages 35-36.
- <sup>243</sup> AIHW Indigenous Health Performance 2020 see note 238: at page 25.

- <sup>244</sup> AIHW Indigenous Health Performance 2020 see note 238: at page 35.
- <sup>245</sup> AIHW Indigenous Health Performance 2020 see note 238: at page 35.
- <sup>246</sup> Australian Institute of Health and Welfare. (AIHW) Aboriginal and Torres Strait Islander Health Performance Framework 2017 Report ACT. Cat no IHW 188. AIHW 2017 Canberra.
- <sup>247</sup> See, for example, Data Sources and Quality -<u>https://www.indigenoushpf.gov.au/Resources/Technical-appendix/Data-sources-quality</u>; and Data quality statement: Admitted Patient Care 2016-17 <u>https://meteor.aihw.gov.au/content/index.phtml/itemId/724186</u>.
- <sup>248</sup> Australian Health Ministers' Advisory Council (AHMAC). National Strategic Framework for Chronic Conditions. (AHMAC Chronic Conditions Framework 2017) Australian Government 2017 Canberra: at Foreword.
- <sup>249</sup> AHMAC Chronic Conditions Framework 2017 see note 248: at page 6.
- <sup>250</sup> AHMAC Chronic Conditions Framework 2017 see note 248: at page 8.
- <sup>251</sup> Department of Health (Australian). National Strategic Action Plan for Lung Conditions. February 2019. Department of Health 2018 Canberra ACT. At: <u>https://www.health.gov.au/resources/publications/national-strategic-action-plan-for-lungconditions</u>. (Lung Disease Action Plan 2019): page 3.
- <sup>252</sup> National Health Reform Agreement (NHRA) Addendum 2020-25, page 56, clause C1(c). Available at: <u>https://www.health.gov.au/initiatives-and-programs/2020-25-national-health-reform-agreement-nhra</u>.
- <sup>253</sup> Australian Government Department of Health. 2020-25 National Health Reform Agreement (NHRA), Australia's long term health reforms section. Available at: <u>https://www.health.gov.au/initiatives-and-programs/2020-25-national-health-reform-agreementnhra.</u>
- <sup>254</sup> NHRA 2020-25: see note 252 at page 60.
- <sup>255</sup> Productivity Commission. *Innovations in Care for Chronic Health Conditions*. 2021 Productivity Reform Case Study, Canberra.
- <sup>256</sup> The AIHW data used in the Productivity Commission report showed that the expenditure on all respiratory conditions totalled \$4,044 million, 24% of which was incurred in relation to COPD. See AIHW. *Disease expenditure in Australia*. 13 June 2019, web report, especially in Australian Burden of Disease conditions, which allows calculation of the proportion of the expenditure by condition and expenditure type. <u>https://www.aihw.gov.au/reports/health-welfare-</u> <u>expenditure/disease-expenditure-australia/contents/australian-burden-of-disease-conditions</u>.
- <sup>257</sup> ACSQHC 2021 see note 44 pages 69-84.