Respiratory Care Action Plan

2021 - 2026

Scottish Government
Riaghaltas na h-Alba
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Ministerial Foreword

Chronic respiratory disease has a major impact on people's lives; as well as their families and carers. Many people living with a respiratory condition are not able to work, study, drive or live independently. In Scotland, respiratory conditions account for over one third of all acute hospital admissions and are also one of the most commonly presented conditions within primary care.

In 2020, clinicians were faced with the new challenge of COVID-19, the main target of the virus being the lungs. Many respiratory doctors, nurses and Allied Health Professionals were redeployed into frontline COVID-19 wards to treat people with severe infections. This has caused unprecedented disruption and change to the way respiratory care is delivered.

Every winter, people living with a respiratory illness such as asthma, COPD or Bronchiectasis, try to protect themselves from the Flu virus. In 2020, people living with these conditions protected themselves and others from the new virus by shielding. We know that the physical and mental toll of shielding has been significant for people living with respiratory illness and we are therefore committed to improving access to rehabilitation services and mental health support.

The publication of the Respiratory Care Action Plan identifies key priorities and commitments to improve outcomes for people living with respiratory conditions in Scotland. The plan encourages new and innovative approaches and intends to share best practice. It sets out our desire to see a whole system approach to respiratory care, across health and social care and our priorities and commitments will build on the progress that has been made to date.

To deliver the most effective, person-centred care we will continue to work collaboratively with key stakeholders in the implementation of our priorities. We are committed to designing and developing services that meet the needs of everyone, with a focus on those that are experiencing health inequalities.

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We thank all of those involved in the care, treatment and support of people living with respiratory conditions. By progressing the commitments and priorities laid out in this ambitious Respiratory Care Action Plan, we will ensure respiratory care meets the needs of the respiratory community in Scotland.

Mairi Gougeon MSP
Minister for Public Health and Sport

Clinical Forward

Respiratory illnesses present commonly to primary care teams, and represent over one third of acute medical intake in most Scottish hospitals. The ageing population, advances in primary and secondary prevention of cardiovascular diseases, and improvements in acute and chronic management for respiratory complaints means the pressures placed on secondary care respiratory units is far greater than ever before. Ensuring people see the right health care professional, in the right setting, at the right time, continues to be demanding. We face challenges of prioritisation of those people with serious illnesses; providing access to diagnostic testing to allow primary care clinicians to make independent decisions with their patients; streamlining referral pathways to ensure those with the greatest need are seen quickest, while providing support to those who wait longer; and providing high quality ongoing care for people with chronic respiratory disease.

In 2020 and beyond, Scotland faced the largest public health challenge of a generation in the COVID-19 pandemic. Primary and secondary care teams faced an overwhelming burden of disease which presented mainly as respiratory distress; secondary care respiratory clinicians held a key role in the assessment and management of people with COVID-19, including treatment of critically unwell patients. COVID-19 changed the way respiratory clinicians work: the effects of these changes will be felt for years, in many respects respiratory medicine will never be the same again. It is essential that we recognise the effects of COVID-19 on those people who were infected, those whose disease management was altered due to the pandemic both directly and indirectly, and those people who will develop new chronic symptoms, or have worsening of their underlying condition, due to infection. There have been improvements to services due to the COVID pandemic: increased use of remote consultations has improved access to clinical care, reduced the burden of travel, and released clinicians from the constraints of clinical space; closer working between primary and secondary care teams to provide joined up care during the patient journey has been welcomed; increased awareness of infection control measures in the community has reduced the incidence of viral and bacterial respiratory illnesses dramatically in 2020. However, critical services such as pulmonary rehabilitation classes have been severely limited due to social distancing guidelines – an issue that needs to be tackled with the upmost priority.

The respiratory conditions in this Plan - asthma, COPD, idiopathic pulmonary fibrosis, bronchiectasis and obstructive sleep apnoea syndrome - make up the majority of the workload of respiratory physicians in Scotland. Although each presents its own challenges, there are problems common to all respiratory conditions. There is a strong evidence base for these conditions, and straightforward measures that can be taken to improve outcomes. Pulmonary malignancy is a clinical priority covered by other guidance.

Respiratory medicine will never be the same as it was pre-COVID. Investment in respiratory medicine has never been as important as it is now – provision of high quality, joined-up respiratory care across Scotland must be the priority. New investment in well trained, multi-disciplinary healthcare teams is critical, right now. The Respiratory Care Action Plan provides the key priority areas for large scale improvement in respiratory care in Scotland.

Dr Tom Fardon
Consultant Respiratory Physician
NHS Tayside

Introduction

What is this Plan?

The purpose of this Plan is to set out our vision for driving improvement in the diagnosis, care, treatment and support of people living with respiratory conditions in Scotland.

The Plan identifies five key priorities for respiratory care in Scotland. It is intended to be an enabling document which will continue to drive continuous improvement. The plan is not intended as a replacement of current clinical guidance, but brings together good practice from across Scotland.

The Plan aims to build on what already works well and challenge traditional models that may not be providing the best solutions for people living with a respiratory condition. Respiratory services have had to adapt quickly due to the direct and indirect impacts of the COVID-19 pandemic and through engagement with the respiratory community, we hope that this document reflects the progress that has been made as well as address the additional challenges we now face.

This Plan does not set out detail of how this will be achieved – this will be determined in the implementation phase of the Plan. We will work in partnership with the respiratory community to implement the commitments set out in this Plan. We know that the way services are delivered is changing at pace due to the COVID-19 pandemic and we want to ensure this change is reflected. The implementation programme will be fluid and we will continue to evolve our approach to respiratory care in Scotland as our understanding of the impact of the pandemic grows and ensure our actions are relevant.

Who is this Plan for?

This plan is for the anyone in Scotland living with a respiratory condition, as well as anyone working within health and social care or the third sector. This plan also takes into account people who may not yet have a diagnosis, or are currently on a pathway to be seen by respiratory services.

We want to ensure that people living with respiratory conditions have access to the best possible care and support. To achieve this, we have developed the Plan with the help of healthcare professionals, policy

makers, third sector organisations and people living with a respiratory condition in Scotland.

How will this Plan drive improvement?

This document is intended to support health care professionals delivering respiratory care in NHS Scotland, as well as wider respiratory services in the third sector. This Plan will be supported by an implementation programme and subsequent measurement plan. We intend to establish a Scottish Government led National Advisory Committee, who will have a key role in the design and implementation of projects under each of the commitments and priorities. We will also ensure the voice and experience of people living with a respiratory condition is weaved throughout implementation.

We will also work towards establishing an improved data set, which will identify areas of excellence, opportunity and concern. Any data we build should be simple and accessible for health and social care staff to use and should inform all implementation projects.

Chapter One

Respiratory Conditions

Although 'respiratory condition' is a general term used to describe a large group of conditions that impair the airways and lungs, this plan is aimed at five specific lung conditions that make up over 90% of the burden of respiratory disease in Scotland. Other conditions affecting the lungs (for example, lung and pleural cancer and rare diseases such as cystic fibrosis) are already included within other Scottish Government strategies[i].

The 5 conditions in the Plan are:

- Asthma
- Bronchiectasis
- Chronic Obstructive Pulmonary Disease (COPD)
- Idiopathic Pulmonary Fibrosis (IPF)
- Obstructive Sleep Apnoea Syndrome.

What are respiratory conditions?

Respiratory conditions are diseases of the airways and other structures of the lung. They are a major contributor to ill-health, disability and premature death. The most common of these are asthma and chronic obstructive pulmonary disease (COPD). The World Health Organisation has identified chronic respiratory disease as one of the four leading non-communicable diseases worldwide, along with cardiovascular disease, cancer and diabetes[ii].

Although most long-term respiratory conditions are not curable, various forms of treatment have been shown to help control symptoms and increase the quality of life.

Impact of respiratory conditions

The impact of respiratory conditions varies from person to person and can depend on many factors. Some people suffer chronic symptoms which have a significant impact on their life and those around them. Breathlessness and unpredictable exacerbations mean people become unable to work or study full time. Some people become socially isolated because they cannot participate in activities. Trips to Emergency Departments are also common and many people report traumatic events of being admitted to hospital for long periods of time. There is also a high incidence of heart disease, hypertension and diabetes within the

respiratory patient group, which means some people have multiple health conditions to manage and multiple anxieties around their care and treatment.

Every winter, the risk of contracting flu adds additional strain to people's health and on the health service. In 2020, the risk of contracting COVID-19 led to significant life changes for many people living with respiratory conditions; and the long term psychological impact of this should not be underestimated. Anxiety and depression were already commonly reported and diagnosed in people living with respiratory conditions, but this is thought to have increased over the course of the Pandemic, as reported by a British Lung Foundation survey[iii].

Family members and carers can also be affected by the impact of living with and supporting someone with a respiratory condition. For example, a diagnosis of IPF can cause huge anxieties for spouses and family members. Others may have to give up work to become full time carers as conditions progress and worsen.

Development of the Respiratory Care Action Plan

Dr Tom Fardon, consultant physician in respiratory and general internal medicine in NHS Tayside established condition specific multidisciplinary groups to develop an understanding of the care and support currently available, existing gaps in service provision, examples of good practice and clinical priorities for improvement. The issues raised at these condition specific work stream meetings are reported in Annex A. Output from these groups has helped to inform the development of the Plan. The draft Plan was then put to a public consultation via the Scottish Government website in December 2019. The consultation received 120 responses from individuals and organisations over the period; which was extended to July 2020 in light of the pandemic.

The COVID-19 Pandemic

Since the publication and consultation of the draft Plan in December 2019, life has changed significantly across the world as we faced a global pandemic. In March 2020, NHS boards encountered unprecedented pressure and people were asked to stay at home to protect the NHS and save lives. Routine care was almost entirely paused as staff were redeployed across the sector. As NHS Boards remobilised services in 2020 and 2021, many aspects of routine care have remained in place thanks to virtual alternatives.

The impact of COVID-19 on health services has been, and continues to be momentous. For people living with a respiratory condition, this pandemic has been a double edged sword. The risk of contracting an airborne virus is a risk people face every winter and flu season; so many had started to shield as soon news of the virus broke. During consultation and subsequent engagement with third sector community groups, many people stated that leaving their home was too great a risk to take. Some found themselves with huge dilemma's: travelling to busy hospital sites for treatment or staying at home and missing out on potentially crucial interventions. Some hospital sites stopped aerosol-generating procedures – meaning people had to travel to specific 'hot-zones' where they could be done safely.

Assessment of pulmonary function by forced expiratory manoeuvres is one such aerosol generating procedure which can no longer be carried out in the community, and is limited to specific hospital environments. This has slowed down assessment of pulmonary function, and provided significant challenges in the investigation, diagnosis, and management of airways disease. CPAP (Continuous Positive Airway Pressure), the treatment for obstructive sleep apnoea, is also an aerosol generating procedure, and decisions within households whether to use this during the pandemic have been challenging.

The longer term impact of this pandemic on respiratory services could be generational. The gaps in health inequalities are also now increasing and this has become apparent through work such as the Cosette Report[iv] which found people from Black and Ethnic Minority groups have been disproportionately impacted. Data suggest that pre-existing lung conditions do not predispose people to contracting COVID-19, as was initially feared, however those people with severe respiratory illness are less able to cope with the burden of the disease.

However, it is important to consider the secondary impact of this pandemic for these people. Delays to referral, investigation, and initiation of management; late presentation of new diseases, as well as the psychological toll of isolation and shielding. Over 80,000 people in Scotland with a respiratory condition were asked to shield; the largest group of people within the shielding list.

Some respiratory services have continued throughout the pandemic. Urgent suspected cancer clinics have been maintained throughout, along with outpatient services for urgent respiratory concerns. In-patient services have also continued and there has been a reduced impact of flu season, due to the widespread adoption of facemasks, hand hygiene, social distancing, and shielding.

Hospital and community respiratory teams have played a key role in the COVID-19 response across Scotland. New methods of working to ensure the

safety of all patients, with or without COVID-19 infection, have delivered improvements that should be maintained and spread as we move forward.

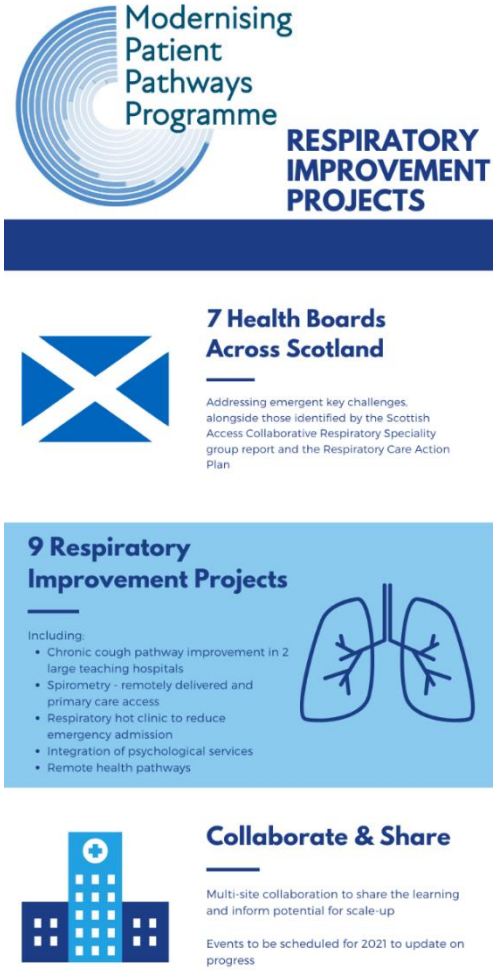
The first draft of this Plan, which has been widely consulted on, has now been updated to reflect the unprecedented changes to people's health and healthcare service. We have written this Plan based on services remobilising mid-2021 but want to ensure all of the good practice and innovation from 2020 can be captured and built into services moving forward.

Contributing Policy

Although the overarching policy responsibility for respiratory conditions sits within the Clinical Priorities team in the Scottish Government, we have collaborated with many other teams and programmes to develop this Plan.

Scottish Access Collaborative & Modernising Patient Pathways Programme

The Modernising Patient Pathway Programme (MPPP) is working towards Improving patient journeys by delivering sustainable changes to support safe, effective, and person-centred care. In 2020, several respiratory projects were initiated.



The Scottish Access Collaborative was established in the autumn of 2017 to reform elective care services. The Collaborative focuses on a number of challenges including referral processes, streamlining return outpatient appointments and capacity planning.

For the respiratory programme, members of the Specialty working group came from 16 specialist areas and 6 different NHS board areas, giving the sub-group both a broad geographic and functional reach. This programme took the approach of identifying common respiratory symptoms, and then mapped each symptom against areas for improvement. This symptom based approach to respiratory care provides useful counterpoint to the disease specific approach provided by this Plan; both documents work together to provide a

vision for the care of people with respiratory conditions in Scotland.

We will continue to work closely with both programmes and use learning from the respiratory projects to inform our wider implementation programme.

Rehabilitation Framework

In August 2020, the Scottish Government published the Framework for supporting people through Recovery and Rehabilitation during and after the COVID-19 Pandemic[v]. This paper provides a strategic framework with overarching principles and high-level recommendations, which will inform and shape the provision of rehabilitation and recovery services across Scotland for the COVID-19 period and beyond. The rehabilitation programme will work with a wide range of stakeholders and is governed by a National Advisory Committee.

We will work closely with the Rehabilitation Framework programme to ensure that the pulmonary rehabilitation is a key focus in the implementation of the Framework.

Long-Covid

As the pandemic has progressed, there has been an increase in public and clinical awareness of some longer-term effects of COVID-19 infection. This has been referred to as 'Long-COVID' or 'post-COVID syndrome'

Emerging evidence shows that a significant proportion of people who have contracted COVID-19 go on to have extended rehabilitation support needs. This is not limited to Intensive Care survivors and those who received acute hospital care where needs can be complex and varied. A significant proportion of people that experienced milder symptoms during their initial illness are now struggling with a range of longer lasting symptoms.

The condition usually presents with clusters of symptoms, often overlapping, which may change over time and can affect any system within the body, including the respiratory system. People with Long-COVID can also experience generalised pain, fatigue, persisting high temperature and mental health problems.

The NHS in Scotland is already delivering care tailored to the individual needs of people experiencing the long-term effects of COVID-19 through local primary care teams, community based rehabilitation services and specialised secondary care where needed. However, we know that additional support along with new ways of working are also required if

services are to provide timely and equitable support to all who need it. A multidisciplinary approach will be key to supporting people with such a broad range of symptoms.

Rehabilitation, clinical input and research are all critical to understanding and supporting recovery - and it is crucial that decisions about our response to Long-COVID are based on the latest available evidence.

It is critically important there is investment in providing support for people with Long-COVID and this is just one part of the package that is needed to provide the diagnosis, care and support that people need so urgently.

There is still much to learn and a great deal to be done, but Scottish Government, along with our partners are committed to working together to ensure people have access to the right services at the right time. As we continue to learn and respond to the pandemic, it is crucial that the decisions we take are based on the latest available evidence and are aligned to clinical guidance.

Our Vision & Aims

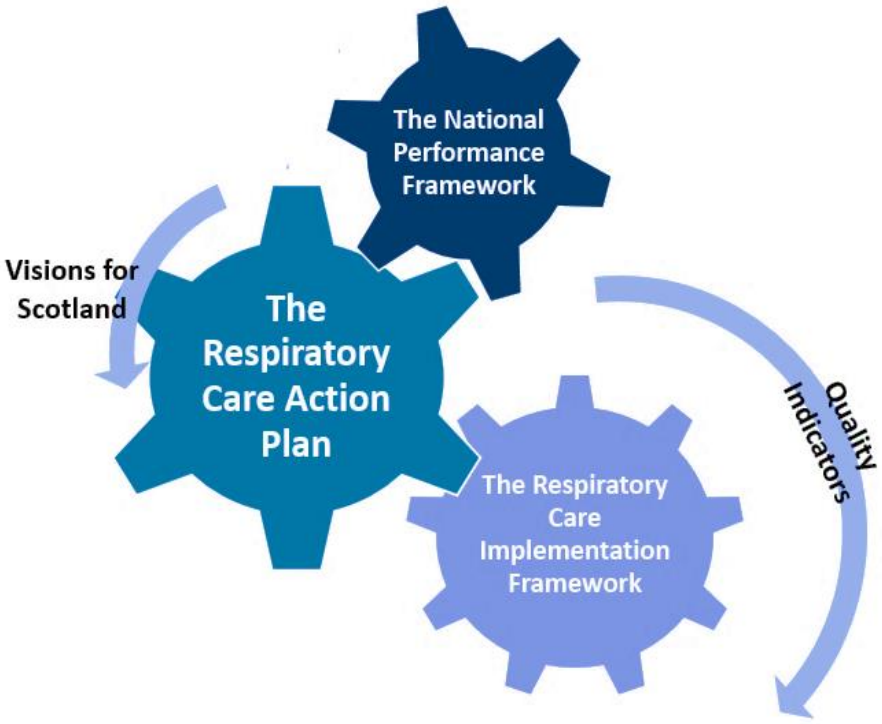
This Plan outlines a strategic approach to support health and social care stakeholders in the prevention, diagnosis, treatment and care of respiratory conditions, in order to achieve our vision:

Everyone with a respiratory condition will be able to access the care and support they need to live well, on their own terms.

We recognise that a collaborative approach is required in order to transform and improve the care of people living with respiratory conditions in Scotland. All policy in Scotland is underpinned by the vision and values of the National Performance Framework. To achieve the national outcomes, the National Performance Framework aims to get everyone in Scotland to work together.

Although this Plan covers the next five years, we intend for the RCAP Implementation Programme to be fluid and adapt to the pace of changes currently happening within health and social care. We need to work towards building meaningful data sets and from that, a set of indicators which will help us monitor progress and also track unmet need.

Under the five key priority areas, this Plan outlines a set of high level Commitments that the Scottish Government are making to improve respiratory care in Scotland. These commitments are broad ranging and intended to cover all of the key areas of opportunity highlighted during scoping work with the respiratory communities. These Commitments do not explicitly set out actions, but will form the basis of an implementation programme. A summary of these Commitments can be found in Annex B.



We will ensure a robust governance system by forming a National Advisory Group and ensure that the voice of people with lived experience informs all of the implementation phase. Wider policy developments will be monitored and using quality indicators, we will measure success of the programme over time.

Priority Areas:

1:	Prevention
2:	Diagnosis, Management & Care
3:	Supporting Self-Management
4:	Consistent Access Across Scotland
5:	Our Workforce

Chapter Two

Priority 1 - Prevention

Environmental and lifestyle factors play a significant role in the burden of respiratory conditions and we know that the pandemic has heightened risks for some vulnerable groups of people in Scotland. In order to reduce exposure to the known risk factors such as tobacco, cold homes, air pollution, obesity and respiratory infections, we must collaborate across multiple sectors.

The Scottish Government has set out ambitious aims through its Strategies and Plans to ensure preventative approaches are a priority. All of these strategies have a clear focus in tackling the health inequalities faced by many groups across Scotland.

For respiratory disease, we will consider:

1.1 Tobacco & Smoking
1.2 Clean air
1.3 Warm Homes
1.4 Vaccinations
1.5 Diet & Healthy Weight

1.1 Tobacco

The World Health Organisation describe tobacco as 'one of the biggest public health threats the world has ever faced,' with more than 7 million deaths worldwide as a direct result of tobacco use and a further 1.2 million attributed to second-hand smoke exposure. As the cause of around one in five deaths and the primary preventable cause of premature death, smoking represents the chief threat to Scotland's public health . Smoking rates continue to be highest in Scotland's most deprived areas, underlining smoking as a key ongoing health inequality challenge.

The Scottish Government published its five year strategy 'Raising Scotland's Tobacco Free Generation' in June 2018, The action plan sets out interventions and policies to help reduce the use of and associated harms from using tobacco in Scotland. This Plan focuses on the inequalities within groups of people that smoke, prevention and reduction of uptake of

smoking among young people and providing the best possible support for those people who want to give up.

The Scottish Government have introduced a 2034 tobacco free target. Our aim is to reduce smoking rates to 5% or below by 2034, creating a generation of young people who do not want to smoke and are protected from the harms of smoking. The Tobacco-Control Action Plan 2018; Raising Scotland's Tobacco-free Generation, continues our work on protecting children from taking up the habit of smoking and creating a tobacco-free generation by 2034.

The NHS free stop-smoking service was rebranded in 2018 with the emphasis on helping people find their own way to stub out the habit. The free Quit Your Way helpline provides a uniform service across Scotland with smokers offered specialist support and advice.

The health impact of smoking in relation to respiratory conditions, cannot be underestimated. Therefore it is critical that this Plan and subsequent implementation programme collaborates with the tobacco policy team and wider public health services. Whilst this draft Plan contains specific commitments in relation to respiratory conditions, we must not lose sight of broader aims.

The emergence of Nicotine Vapour Products (NVPs) over the past decade has added another dimension to the landscape. A consensus statement; created by NHS Scotland in collaboration with over 20 expert groups in the field including the Royal College of Physicians and Surgeons of Glasgow, the University of Stirling and the campaigning public health charity, Action on Smoking & Health (ASH) agree that, "based on the current evidence, vaping e-cigarettes is definitely less harmful than smoking tobacco." They are useful only as a potential route towards stopping smoking and should not be used by children or non-smokers.

There remains a lot that we do not know about NVPs and the potential long-term negative impact on respiratory health. While less harmful than tobacco, they are not risk free and, along with being the first country to devise a specific quit vaping programme, we plan to introduce stricter controls on the advertising and promotion of NVPs in Scotland. A full public consultation on NVPs is hoped to be launched in 2021.

The COVID-19 pandemic has raised a number of concerns around the ability of smokers to fight a COVID-19 infection. While evidence on this subject is mixed, the World Health Organisation has stated that smokers are at higher risk from contracting the illness and becoming more severely unwell as a result.

As well as well as helping current smokers to quit and reducing exposure to second-hand smoke, policy advocates health and wellbeing education including messaging about the harms of smoking. One such initiative was the Border and Regions Airways Training Hub (BREATH) which worked with a number of organisations researching chronic obstructive pulmonary disease (COPD) to raise public awareness of the condition and alleviate its impact. Academics and PhD students from the University of the West of Scotland took the programme to schools in Dumfries and Galloway – an area where COPD related hospital admission is amongst the highest in the UK.

1.2 Clean Air

The Scottish Government is also taking decisive action to improve air quality. We recognise the impact that poor air quality can have on human health, especially on the young, elderly and those with pre-existing health conditions. Compared to the rest of the UK and other parts of Europe, Scotland has a high level of air quality.

We have set more stringent air quality targets than the rest of the UK. Our commitment to introducing Low Emission Zones in our four largest cities is a key initiative in further improving urban air quality, the first of which has already been introduced in Glasgow.

An independently led review of our air quality strategy 'Cleaner Air for Scotland – The Road to a Healthier Future' to assess progress and identify priorities for further action, has been completed and will be used as the basis for developing a revised and updated strategy. A report setting out the conclusions and recommendations of the review was completed in 2019. The recommendations arising from the review have been used to draft a new air quality strategy. A public consultation on the draft concluded in January 2021 and the finalised strategy will be published later in 2021.

Improvements in air quality was raised as a key concern by many individuals during the consultation. We will continue to work closely with the Cleaner Air for Scotland programme.

1.3 Warm Homes

Cold-related deaths are a significant weather related source of mortality. The reason more people die in the winter compared to other times of year are complex, however one of the main causes is thought to be related to cold homes. Cold homes are often the result of poor quality housing and poverty, which poses a significant risk to the development or exacerbation of respiratory disease.

Fuel poverty is defined as a household where more than 10% of its net income (after housing costs) is required to heat the home and pay for fuel costs, and if after deducting fuel and childcare costs and disregarding the value of specified benefits which are received for care need or disability, the remaining net income is insufficient to maintain an acceptable standard of living for the members of the household, defined as 90% of the UK Minimum Income Standard (MIS).

The Scottish Government is committed to reducing the impact of fuel poverty and whilst COVID-19 has caused us to pause development of the Fuel Poverty Strategy, this work will resume as soon as possible and we aim to publish the final Fuel Poverty Strategy in 2021.

The Scottish Government believes that everyone in Scotland should have a safe, warm place to call home, but we know the COVID-19 pandemic has caused many people to worry about the cost of their fuel bills.

We are also determined to reduce the widening fuel poverty gap and will continue providing enhanced support through our energy efficiency schemes in remote rural communities in recognition of the generally higher costs and already provide enhanced support through our energy efficiency schemes in recognition of the generally higher costs of installation work in these areas.

1.4 Vaccinations

People with chronic lung diseases are significantly more likely to get flu and are more likely to require admission to hospital if infected[vi]. We know that the flu vaccinations for people living with lung disease can reduce hospital admissions by up to 52% and reduce mortality by 70%. In 2020,

uptake of the flu vaccine increased[vii] and there were also less admissions to hospital with flu.

In 2018, the contract for General Practice introduced a new model for vaccine delivery across Scotland and the roll out of the COVID-19 vaccine at the end of 2020 has transformed the way people think about vaccination.

The COVID-19 vaccine roll out has required many additional staff to be trained to vaccinate and a significant public health campaign has increased knowledge and awareness of the benefits of vaccinations. We will continue to monitor the development and roll out of vaccination programmes and the role they play in respiratory disease.

1.5 Diet and Healthy Weight

In July 2018 the Scottish Government published 'A Healthier Future: Scotland's Diet & Healthy Weight Delivery Plan', following consultation with stakeholders.

The Plan sets out a vision where everyone in Scotland eats well and has a healthy weight. Among its aims are to reduce diet-related health inequalities significantly. The Plan includes actions to transform the food environment, including restrictions on the promotion of foods high in fat, sugar or salt where they are sold to the public. Population-wide interventions are likely to be more effective in reducing inequalities as they do not rely on individual behaviour change. The Plan also sets out targeted and tailored support to those individuals, children and families who need it most. As well measures to prevent overweight and obesity, the Plan includes actions to improve access to effective weight management services.

As poor diet and excess weight can lead to increased risk of respiratory conditions, implementing the Diet and Healthy Weight Delivery Plan plays an important role in their prevention. Supporting people to eat well and maintain a healthy weight must be integral to our work in reducing the risk of people developing respiratory conditions.

Commitment 1

We will work with all relevant policy areas to ensure preventative measures are embedded in all aspects of respiratory care.

Priority 2 - Diagnosis, Management and Care

2.1 Early and Correct Diagnosis

Early and accurate diagnosis of respiratory conditions can enable treatment and support to begin before the disease has progressed. When people are given information about their condition early, they have more opportunity to explore self-management techniques and may be able to avoid more intensive treatments.

Late diagnosis, under-diagnosis and misdiagnosis can have significant impact on the long term outcomes of respiratory conditions and on a person's quality of life. We know that surveillance and screening are key to early diagnosis and ultimately better health outcomes for the individual.

To diagnose respiratory conditions correctly and provide the best care possible, healthcare professionals need ongoing education. This requires access to equipment and up to date guidance on a regular basis. In order to grow the diagnostic capacity within the NHS, respiratory specific education should be made available to a wider group of professionals including pharmacists, Allied Health Professionals (AHPs) and Health Care Support Workers (HCSWs) in primary, secondary and community care environments.

Access to diagnostic tests may be inconsistent across the country. There are national guidelines for diagnosing respiratory disease, which inform the use of specific tests including x-rays and CT scans, pulmonary function testing, blood tests and polysomnography (sleep studies). For people exhibiting symptoms of a respiratory condition, the route to diagnosis may not be straightforward. Along with wider health and social care policy, we understand that access to diagnostic testing needs to improve, but we also need to consider barriers to accessing health information and support.

During the COVID-19 pandemic, new diagnoses may have been missed. People were initially asked to stay at home, meaning some people will not have sought advice from their GP Practice due to fear of burdening the NHS. People identifying a cough when calling their GP practice may have been redirected to a COVID-19 testing pathway. Access to diagnostic testing has also been challenged because of reduced service capacity for pulmonary function testing in particular, as it is an aerosol generating procedure and therefore higher risk to carry out during the pandemic. It is

critical that timely diagnosis is in place moving forward and consideration must be taken on how to tackle missed or delayed diagnoses as a result of COVID-19.

Upon diagnosis, people should then enter an appropriate treatment pathway, which is supported by safe, effective prescribing. Medicines for respiratory conditions are constantly evolving and we will work closely with medicines policy teams to ensure this Plan is linked with the update of the Quality Prescribing for Respiratory guide.

Commitment 2

We will improve and simplify access to appropriate diagnostic tests for respiratory conditions and explore the use of high quality, consistent spirometry testing and chest & lung CT scans.

Commitment 3

We will support the ongoing work within the Scottish Access Collaborative' disease-specific pathway projects and ensure developments are embedded within wider respiratory policy.

2.2 Pulmonary Rehabilitation

A critical part of the respiratory care pathway is access to pulmonary rehabilitation.

Pulmonary rehabilitation offers a structured exercise and education programme designed for people living with a respiratory condition. The programme encourages increased physical activity within the person's limitations. Throughout the programme, participants are offered advice about their own specific medications and how to use them, as well as information on diet, weight management and mental health support.

Pulmonary rehabilitation is one of the most effective forms of management for people living with respiratory conditions. 90% of people who complete the programme experience improved exercise capacity or increased quality of life[viii]. However, Chest Heart and Stroke Scotland (CHSS) estimates that only 2% to 21% of those who might benefit are being referred to pulmonary

rehabilitation[ix]. Pulmonary rehabilitation is best established within treatment for COPD, however there is evidence of clear benefit in asthma, pulmonary fibrosis and bronchiectasis.

NHS Boards are expected to provide access to accredited pulmonary rehabilitation programs based on current clinical guidelines[x]. In order to improve and widen access, we need to think differently and communicate the health benefits to a broader audience. Demand for the service will likely increase in the wake of the COVID-19 pandemic. During consultation of this Plan, many health professionals highlighted the need to work with community services in order to promote pulmonary rehab to more vulnerable groups.

Some NHS boards across Scotland have adapted to deliver pulmonary rehab virtually. Although this has been an excellent example of innovation, it is not regarded as a long-term solution by many people using the service. The social aspect of classes was highlighted as a huge benefit by many individual respondents during the consultation. The changes in lifestyle caused by the COVID-19 pandemic have meant that communication, meetings and social interactions over digital media are now commonplace, and more widely accepted by all age groups.

The Rehabilitation and Recovery Framework will support rehabilitation service development in the future. This work will be relevant to the implementation programme as it covers three target groups:

- Those that had COVID-19 and have extended rehabilitation needs
- Those that have had pre-existing health conditions that have been negatively impacted by lockdown restrictions
- Those that required ongoing intensive rehab as a result of services or treatment delayed due to COVID-19

Moving forward, we should consider best practice before and during the pandemic and consider how we can make future pulmonary rehabilitation sustainable. We must design pulmonary rehabilitation based on the needs of people and specifically aim to increase uptake in groups with the highest incidence of respiratory conditions.

Commitment 4

As part of the Rehabilitation Framework implementation programme, we will ensure everyone with respiratory conditions who would benefit from specialist, general and community rehab is able to access appropriate services and support.

2.3 Mental Health Support

Diagnosis of a respiratory condition can have a profound effect on mental health and wellbeing. Unlike other disease groups such as cancer, there is currently no specific pathway for mental health input for a new respiratory diagnosis. Some health boards complete a mental health psychological assessment during pulmonary rehab, however this is not consistent. Within other condition specific pathways, there are examples of good practice such as the 'holistic health assessment' used by some cancer services. This includes not only a mental health assessment, but considers wider factors including finance, employment and relationships.

A new diagnosis of IPF for example, can have a lower life expectancy than some forms of lung cancer. There is no way to stop IPF and there is currently no cure. This can be an extremely traumatic time for people and their families, and access to mental health support is difficult to navigate for a condition like IPF. People who have a new diagnosis of a respiratory condition, or have lived with their diagnosis for some time commonly have feelings of anxiety, low mood, and depression. During the COVID-19 pandemic, many people reported heightened anxiety and depression.

We know that the Pandemic has increased demand for mental health services and the impact of this is likely to be long lasting. This may mean there is reduced capacity within the system to create condition-specific responses, so we must continue to link with developments happening across other areas. We will not accept that patients should have to wait for prolonged periods to receive the support and treatment they need from mental health services.

The Scottish Government published the Mental Health Transition and Recovery Plan in October 2020 in response to the pandemic and recognised the need to integrate our response to mental and physical health. We will continue to place clinical and strategic priority upon achieving parity between and across mental and physical health.

Commitment 5

We will work with people living with respiratory conditions to better understand the barriers to accessing appropriate mental health support; and collaborate with policy and health & social care teams to determine opportunity for improvements.

2.4 Transition from Child & Young People Services to Adult Services

Children can be diagnosed with several lung conditions, however the most common is Asthma. One of the most important aspects in the management of asthma is the period of transition from childhood to adulthood.

If children receive a respiratory diagnosis in early life, their care is provided by a paediatric team. The transition to adult services occurs at different stages dependent on the young person, their diagnosis, and the infrastructure of the paediatric and adult services within their region. This transition period occurs for all long term conditions and can be a challenging time for young people and their families or carers.

During adolescence, care can become fragmented due to transition from paediatric to adult services. Changes in priorities for young people can lead to disengagement from clinical services; feelings of independence can also be accompanied by feelings of resistance towards therapies.

To ensure a positive transition, both teams should work together to create a person-centred plan, and ensure this is done in partnership with the young person and their family or carer.

Commitment 6

We will work with key partners to understand and improve pathways for a good transition from children and young people services to adult respiratory services, and ensure all young people with long term respiratory conditions go through a dedicated respiratory transition service.

2.5 Palliative Care

Palliative care is about improving the quality of life of anyone facing problems associated with life-limiting conditions. It includes physical, emotional and spiritual care and can be delivered in any setting.

It can be difficult to determine how lung disease will progress, particularly for people with multiple other conditions. Therefore the palliative and end of life care needs of these people should be assessed as early as possible, to

help staff and loved ones to appropriately coordinate care and support. The Scottish Palliative Care Guidelines[xi] reflect good practice in the management of those with life-limiting illness and are designed for healthcare professionals from any care setting who are involved in supporting people with a palliative life-limiting condition.

It is important to understand that starting a palliative pathway does not mean that the disease will no longer be actively managed. Person-centred palliative care takes account of changing preferences and priorities of people with advanced illness and their carers to help staff and loved ones to appropriately coordinate care and support.

Anticipatory care planning (ACP)

Some respiratory conditions can progress rapidly. In such instances, it is particularly important for healthcare professionals to have early care planning conversations with people and their loved ones about their care wishes for the future.

This person centred approach, known as Anticipatory care planning, is a proactive approach to care, where people are supported to have meaningful conversations with their families, friends and healthcare professionals about the things that matter most to them – particularly in the context of their treatment or care. This can include conversations about what to do if there is a sudden deterioration in their health. Individuals can be supported to make an anticipatory care plan with their health professional outlining the types of care and treatment which would be and which would not be appropriate in these circumstances.

Commitment 7

We will work with the NHS, clinicians and the third sector to ensure provision of best practice palliative care for people with a lung condition as they near the end of life and support wider roll out of Anticipatory Care Plans.

Priority 3 – Supporting Self-Management

Every day, people with long-term conditions, their family members and carers make decisions, take actions and manage a broad range of factors that contribute to their health. Self-management is the process each individual develops to enable them to manage their own condition. Self-management does not mean people are left to manage their condition on their own; it requires a strong partnership with health professionals and access to a wide range of support networks.

There are a variety of evidence-based, effective mechanisms for people living with respiratory conditions to manage their own condition. People need to first feel confident in their own knowledge and skills. Healthcare professionals play a crucial in empowering their patients.

Self-management techniques are well established within long-term conditions and during the COVID-19 pandemic, they became more important than ever. With access to hospital and community services disrupted, people were forced to take a different approach to manage their condition. People living with respiratory conditions raised many positive examples of self-management during the pandemic and it is important to share these examples and build into wider service delivery.

3.1 Unpaid Carers

Unpaid carers play a vital role in supporting their loved ones. A carer is anyone who looks after a friend, family member or neighbour due to old age, physical or mental illness, disability, or an addiction (this does not include paid care workers or those who are volunteering). There are around 700,000-800,000 people in Scotland who look after someone else.

'Looking after' can mean helping with things like shopping, domestic tasks, emotional assistance and personal care - all of which are difficult.

Many people living with a respiratory condition rely on support of a paid or unpaid carer. Family members, friends and neighbours providing these roles should be supported so that they can continue to care, if they so wish, and have a life alongside caring.

Support for those looking after someone comes from the Carers (Scotland) Act 2016. The Act extends and enhances the rights of carers in Scotland to help improve their health and wellbeing. We will continue to support people living with a respiratory condition and their carers to access appropriate support and resources. We will work with third sector organisation to help ensure carers of people with respiratory illness are aware of their rights and how to access support.

Commitment 8

We will work with key stakeholders to help ensure carers of people with respiratory illness are aware of their rights and how to access support.

3.2 Peer Support

People living with a respiratory condition can feel isolated and alone. During the COVID-19 pandemic, many people took swift action and began shielding before the shielding advice from the Scottish Government was issued. Although this decisive action protected many from contracting the virus, it has increased the feeling of isolation.

Peer support is regarded as a very effective tool in improving the mental health and resilience of people with long term conditions. There are many examples of successful peer support programmes throughout Scotland, including Breathe Easy Groups and various singing clubs. We will continue to monitor progress of these groups and ensure we build in peer support to wider pathway development.

3.3 Digital & Innovation

There are many digital and paper based tools available to support people with long term conditions and during the COVID-19 pandemic these provided a lifeline for many. There are specific apps designed for people to manage their COPD, which provide guides on inhaler technique and allow people to track their medications and exacerbations.

The Digital Health & Care Institute (DHI), in partnership with many stakeholders including those within private industry, continue to test, develop and roll out digital solutions including the monitoring of COPD from home. DHI continue to progress the digital transformation agenda in Scotland and ensure NHS and clinical teams are supported to access innovation pathways and test beds where they feel there may be an opportunity to transform the way their patients access treatment and care.

For people living with asthma, there are many apps and online tools. The DHI has written a joint position paper with Asthma UK, and produced a project report containing recommendations for a future vision of asthma care[xii]. We will continue to track developments within the digital and innovation space that may be relevant to respiratory care.

Commitment 9

We will work in partnership with key stakeholders including the third sector and DHI to ensure people with respiratory conditions have access to tools, resources and information that support them to manage their own condition.

Priority 4 – Consistent Access Across Scotland

We know that incidence and mortality rates of chronic diseases are higher in disadvantaged groups and areas of social deprivation. This is a complex problem with a range of causes; however we do know that these areas often have a higher rate of smoking, cold homes and fuel poverty.

In these areas, it is important to take a public health approach and design services based on the needs of specific communities. Third sector organisations play a critical role in developing and delivering community-based services that can reach people who often fall through the gaps of traditional healthcare services.

In order to provide the best respiratory care for all people in Scotland, we first need to understand what level of need exists. The rate of undiagnosed asthma and COPD is thought to have increased in 2020 due to the pause of some services. We are committed to improving access to meaningful data, which display the level of respiratory disease in Scotland and help us to understand where people's needs are not being met. We want to understand the variation across Scotland at a national, regional and local level.

Across Scotland, people struggle to access support services. In order to improve this, we need to work together with Health & Social Care Partnerships, local councils and the third sector to understand the barriers people are facing and identify improvements that will lead to meaningful change

This Plan is focused on the delivery of best care for all. A particular focus is needed in supporting people that experience barriers to accessing the appropriate care. We know that specific barriers to access exist; including restrictive working hours, childcare, transport issues, literacy issues and lack of digital infrastructure.

4.1 Meaningful Data

The Atlas of Variation was developed by ISD Scotland and is used to identify clinical intervention done at individual health board level. This data and can help us to understand if there is overuse or overtreatment

across specific disease group. It is now well understood that the impact of medical intervention when it was not necessary can cause greater harm to the patient than doing nothing. The Realistic Medicine approach shifts away from unnecessary and avoidable medical treatments and instead focuses on what can be done to keep people well.

Data from the Atlas of Variation can help to inform targeted improvements specific to different areas of Scotland. It is important to consider the wide ranging landscapes in health boards across Scotland and support service development that is most suitable for each area.

High quality data is important to the NHS as it can lead to improvements in care and safety. Quality indicators can play a role in improving services and decision making, as well as being able to identify trends and patterns and evaluate services.

Commitment 10

We will build on the data within the Atlas of Variation and work towards a core respiratory data set, in order to understand areas for improvement.

Priority 5 – Workforce

The skills required for treatment and care of respiratory conditions are vast and wide ranging. People living with conditions like COPD will come into contact with a range of health and social care professionals on a regular basis. It is important that the we build capacity and capability across the NHS and wider social care sectors to ensure the growing need in Scotland is met.

The COVID-19 pandemic has caused significant strain on our health and social care workforce. Staff were redeployed to new areas, and others had to step away from frontline roles entirely in order to shield. Over the course of the pandemic, the level of sickness has remained higher than normal and we know that this may continue due to Long-Covid and a variety of other factors. Not only were staff contracting the virus and subsequently taking time to recover, but many staff have also reported increased stress and anxiety.

Moving forward, it is important that all services consider the challenges of staff recruitment and retention; and also consider new and innovative models of care to build resilience across the NHS. In many specialities, nurses, Allied Health Professionals (AHPs) and Pharmacists take on Advanced Practitioner roles and are trained to a very high level. These roles protect sustainability within teams traditionally led by one consultant. As the medical workforce is strained, it is important to recognise the wide range of skills available to respiratory departments and build this into future planning.

5.1 Medical Staffing

Medical training is managed at a UK level. The issues within medical staffing are not limited to respiratory services. We know that many rural areas of Scotland find it difficult to recruit to consultant posts and there are several initiatives within Scottish Government and beyond that aim to tackle the sustainability of the medical workforce.

The Shape of Training review[xiii] proposed an important evolution in the development of specialties and their role within provision of healthcare, particularly in the acute sector. The Review highlighted the need to

construct pathways for more generalist consultants. There is also a need to consider the role of respiratory physicians and the potential increased demand from COVID.

NHS Education for Scotland (NES), BMA and other key stakeholders are working collaboratively to explore innovative ways of encouraging applications at consultant level in Scotland. We will continue to work closely with medical recruitment programmes and also support data collection to ensure we understand the unmet need across Scotland.

5.2 Transformation of Nursing Roles

The diversity of the specialist respiratory nurse role across Scotland is not underestimated. Community nursing teams including General Practice nurses district nurses, care home nurses, specialist community nurses and prison health nurses play a key role in supporting people with respiratory conditions. Their remit is broad and they are key to preventing exacerbations through early intervention and supported self-management.

Person centred care including management plans and instruction in the event of any exacerbation are often a key role of respiratory nurses . Like GPs, Practice Nurses are experienced in supporting people to manage their condition. Practice Nurses tend to be a consistent member of a person's care team through regular check-ups and annual reviews prioritised by clinical need.

The Scottish Government's Transforming Nursing, Midwifery and Health Professions (NMAHP) Programme's aim is to ensure consistent, sustainable and progressive NMAHP roles and career pathways, which will see an appropriately skilled workforce contributing to new models of care. The Transforming NMAHP Roles Programme aims to shift the balance of care, by reducing unscheduled care, unnecessary admissions and supporting people to be at home.

Respiratory specialist nurses can work across the primary and secondary care divide, can utilise skills and expertise across a number of different disease processes, but may also specialise in the specific diseases this is underpinned by level 11 education. Respiratory specialist nurses can fulfil a number of extended roles:

- Assessment of airways diseases, including inhaler technique
- Assessment and prescribing medication

- Carrying out and interpreting spirometry
- Airway clearance techniques
- Support and follow up of people receiving monoclonal antibody therapy for asthma
- Initiation and ongoing support for people on CPAP and NIV therapy for OSA and Obesity Hypoventilation
- Cognitive behavioural therapy for anxiety and depression in respiratory illness
- Assessment and provision of long term oxygen therapy
- Palliation of symptoms
- Anticipatory care planning
- End of life care

We will continue to monitor wider developments across nursing roles and ensure appropriate workforce planning is considered to meet the needs of people living with respiratory disease.

5.3 Multi-Disciplinary Teams

Allied Health Professionals (AHPs) play a significant role in the treatment and care of respiratory conditions in Scotland. The development of more advanced roles means we are seeing more AHP-led services.

Rehabilitation is a core part of managing a respiratory condition and we know that early and regular rehab can have a significant impact on the outcomes of respiratory conditions. Traditionally, physiotherapists provide specialised pulmonary rehabilitation, however we know that workforce challenges mean we must work towards more sustainable models of pulmonary rehab with a wider workforce. The Rehabilitation & Recovery Framework has provided an opportunity to test new, innovative models of rehabilitation across the whole sector.

As with nurses, people living with respiratory conditions will come in to contact with many types of AHPs. Physiologists play a key role in providing diagnostic tests and supporting medical teams with ongoing management of conditions. Dieticians, occupational therapists and radiographers are commonly involved in the care of respiratory conditions. All of these professional groups face the same challenges of recruitment, retention and sustainability.

Access to specific professional services can vary across Scotland, and the specific tasks they perform vary from hospital to hospital. It is important

to consider the wide range of AHP skills we have available and build these into a more holistic respiratory service models.

Pharmacists are also becoming well established within the respiratory pathway. During the consultation of this plan, many people reported the huge benefits they found when able to have a conversation with a pharmacist.

As part of the roll out of the 2018 GMS Contract, many GP practices now have a pharmacist within their team. Many respiratory patients also have other health conditions which means a complex range of medicines to take every day. A Pharmacist is able to spend more time reviewing a person's medication and they can spot potential interactions or risks.

Commitment 11

We will support wider workforce planning activity to develop innovative, sustainable workforce models within respiratory services.

5.4 Increasing Respiratory Skills

Presentation of respiratory conditions are common across all areas of health and social care. A baseline level of respiratory knowledge would build resilience in the workforce and would also improve the journey for people with respiratory conditions accessing services out with their speciality team. This would include training on the use of specific equipment and interventions.

We recognise the importance of including wider sectors within workforce planning. There is vast support available within the third sector and we should consider opportunities of developing pathways and partnerships with organisations such as Chest Heart Stroke Scotland and Asthma UK and the British Lung Foundation.

Chest, Heart, Stroke Scotland have rolled out a Scottish-Government funded Hospital to Home programme to support people in the transition period after leaving hospital. The Hospital to Home service enables people to manage their own condition, with support, from home. The service

provides one to one support upon referral for people with respiratory conditions.

In Scotland COPD accounts for highest number of emergency bed days[xiv] annually. We know that an increase in the life expectancy of the population will lead to increased demand for NHS services as people aged over 75 are the most common patient group seen in hospitals. This adds further to the challenges of how to manage the condition more effectively as older people are likely to have a more complex disease profile.

Emergency admissions for people with COPD and other respiratory diseases can cause significant stress and anxiety. We recognise the importance of supporting the work in Unscheduled Care to increase knowledge and skills of managing exacerbations of conditions such as COPD. This work also incorporates increased training and skills for GPs and other primary care staff to ensure exacerbations are prevented or managed at home.

Commitment 12

As clinical guidelines evolve, we will work with key partners, including NHS Education (NES), to ensure relevant and consistent training is made available to a wider group of healthcare professionals and third sector services, across Scotland.

5.5 Social Care

The recent Review of Adult Social Care[xv] identified areas for improvement within social care services in Scotland. The report suggests we need to 'shift the paradigm' from old thinking to new thinking; including collaboration instead of competition and enabling rights instead of managing need. The report made 27 recommendations after a significant period of engagement.

We know many people living with a respiratory condition have regular contact with social care staff and may have been following complex pathways within the system for many years. We will ensure any key learning from the transformation of social care is shared with the respiratory community and incorporated into the implementation programme.

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[xiv] COPD Best Practice Guide (www.gov.scot)

[xv] Independent Review of Adult Social Care - gov.scot (www.gov.scot)

Annex A

Respiratory Conditions and outputs from the workstream groups

This chapter highlights the 5 respiratory conditions contained within the plan and includes the views of the condition specific workstream groups.

It is important to note, that these are the views of a number of clinicians rather than a factual picture of the care system, backed by official data and fact finding.

Asthma

Asthma is a common lung condition that causes intermittent breathing difficulties.

It affects people of all ages and often starts in childhood, although it can also develop for the first time in adults of any age.

Symptoms

Although there is currently no cure there are simple treatments that can control symptoms and reduce the impact on a person's life.

The main symptoms of asthma are:

- a whistling sound when breathing out (wheezing)
- breathlessness
- a tight chest, which may feel like a band is tightening around it
- coughing

The symptoms can sometimes get temporarily worse. This is known as an asthma attack.

Causes

Asthma is caused by swelling (inflammation) of the breathing tubes that carry air in and out of the lungs. This makes the tubes highly sensitive, so they temporarily narrow.

It may occur randomly or after exposure to a trigger.

Common asthma triggers include:

- allergies (for example to house dust mites, animal fur or pollen)
- smoke, pollution and cold air
- exercise
- infections like colds or flu.

Identifying and avoiding asthma triggers can help keep symptoms under control.

Diagnostics

A carefully taken clinical history combined with peak flow measurements, spirometry, and sometimes more intensive testing including exhaled nitric oxide testing, and challenge testing.

Treatment

Asthma is usually treated by using an inhaler, a small device that lets the user breathe in medicines.

The main types are:

- reliever inhalers – used when needed to quickly relieve asthma symptoms for a short time
- preventer inhalers – used every day to prevent asthma symptoms occurring

Some people also need to take tablets, or injections.

The Asthma workstream raised the following issues with the current diagnostics, management and care.

Diagnostics – Spirometry

Diagnostic spirometry is a test which measures lung function in a controlled environment. It is carried out in primary and secondary care environments throughout Scotland.

Although spirometry is available both in primary and secondary care environments. The group thought that, in primary care, the test is not available throughout all Health Boards. However, those areas that do

provide spirometry, access is generally more rapid, and closer to the person's home.

Primary care spirometry training should be standardised, as well as have a clear quality assurance pathway for non-ARTP (Association for Respiratory Technology & Physiology) accredited practitioners. The group believed that waiting times for spirometry are variable, from few days to 6 weeks or more.

The workstream group members suggested that respiratory diagnostic hubs may be a solution to providing high quality, quality assured spirometry, with skilled interpretation.

Standards of care. National and international guidelines recommend person centred asthma action plans focussing on education and self-management. The group thought that access to asthma action plans is not standardised, and there is variation through Scotland.

Biologic therapies for asthma. It was felt that access to, and assessment for, biologic therapies varies across Scotland. There are no nationally agreed protocols for how to assess people for these therapies. Some areas do not have direct access to biologic therapies, or clinicians with expertise in this area. Standardising paperwork, data collection, and measurements of outcome measures should be a priority for difficult asthma services across Scotland.

Difficult asthma. It was highlighted that there is no uniform approach across the country for difficult asthma: some centres have a multidisciplinary team approach, whereas others have a single handed clinician. This is a particular problem for smaller centres, who need to refer to another centre for difficult cases.

Occupational asthma. Occupational asthma is one of a number of occupational lung diseases. It was the view of members of this workstream that there is significant variation in referral rates across Scotland, with no clear pathway in place to facilitate interaction with the Health and Safety Executive and occupational medicine teams.

British Thoracic Society guidelines on asthma suggest that up to 30% of adult onset asthma is related to occupation, and dedicated occupational asthma services should be in place to assess and treat such patients.

Bronchiectasis

Symptoms, Causes, Diagnostics and Treatment

Bronchiectasis is a long-term condition where the airways of the lungs become abnormally widened, leading to a build-up of excess mucus that can make the lungs more vulnerable to infection.

Symptoms

The most common symptoms of bronchiectasis include:

- a persistent cough that usually brings up phlegm (sputum)
- breathlessness
- recurrent lower respiratory tract infections

The severity of symptoms can vary widely. Some people have only a few symptoms that don't appear often, while others have debilitating daily symptoms.

The symptoms tend to get worse if a lung infection is developed.

The lungs are full of tiny branching airways known as bronchi. Oxygen travels through these airways, ends up in tiny sacs called alveoli, and from there is absorbed into the bloodstream.

The inside walls of the bronchi are coated with sticky mucus, which protects against damage from particles moving down into the lungs.

In bronchiectasis, one or more of the bronchi are abnormally widened. This means more mucus than usual gathers there, which makes the bronchi more vulnerable to infection.

If an infection does develop, the bronchi may be damaged again, so even more mucus gathers in them and the risk of infection increases further.

Over time, this cycle can cause gradually worsening damage to the lungs.

Causes

Bronchiectasis can develop if the tissue and muscles that surround the bronchi are damaged or destroyed.

There are many reasons why this may happen. The 3 most common causes in the UK are:

- having had a lung infection in the past, such as pneumonia or whooping cough, that damages the bronchi
- underlying problems with the immune system (the body's defence against infection) that make the bronchi more vulnerable to damage from an infection
- allergic bronchopulmonary aspergillosis (ABPA) – an allergy to a certain type of fungi that can cause the bronchi to become inflamed if spores from the fungi are inhaled

But in many cases, no obvious cause for the condition can be found. This is known as idiopathic bronchiectasis.

Treatment

The damage caused to the lungs by bronchiectasis is permanent, but treatment can help relieve symptoms and stop the damage getting worse.

The main treatments include:

- exercises and special devices to help clear mucus out of the lungs
- medication to help improve airflow within the lungs
- antibiotics to treat any lung infections that develop

Surgery is usually only considered for bronchiectasis in rare cases where other treatments haven't been effective, the damage to the bronchi is confined to a small area, and the person is in good general health.

Possible complications

Complications of bronchiectasis are rare, but they can be serious.

One of the most serious complications is coughing up large amounts of blood, caused by one of the blood vessels in the lungs splitting.

This can be life threatening and may require emergency surgery to treat it.

The Bronchiectasis workstream raised the following issues with the current diagnostics, management and care.

Diagnostics and case finding. The workstream highlighted that some people with bronchiectasis are either undiagnosed, or misdiagnosed with other respiratory illnesses, particularly COPD. Case finding studies have shown that people who receive multiple courses of antibiotics for lower respiratory tract infection have a high probability of underlying bronchiectasis. Case finding targeting these people will identify these patients, and should be introduced in a co-ordinated manner throughout Scotland.

The diagnostic test requires High Resolution CT (HRCT) scanning of the chest. Primary care clinician access to HRCT is not widespread across Scotland, therefore pathways necessarily include referral to secondary care for all suspected cases. The workstream group supported widespread access for primary care clinicians to HRCT scanning to assess people for bronchiectasis.

Other critical investigations include immunology testing, sputum cultures, and vaccination challenges. A pathway for assessment prior to secondary care review could be co-ordinated through respiratory diagnostic hubs.

Secondary care specialist clinics. It was suggested that each hospital should have provision for a specialist bronchiectasis clinic. Centres should have a complex infection multidisciplinary team, involving respiratory clinicians, specialist nurses, microbiologists, pharmacists, immunologists (where available), and ID clinicians. Difficult cases should be discussed at regional or national multidisciplinary team (MDT) meetings. It was the view of the group that a separate National Bronchiectasis Strategy may be given some consideration in the future. This would require investment in both leadership and administration, to facilitate audit and improvement work within the bronchiectasis community in Scotland. It was also highlighted that involvement in EMBARC (Bronchiectasis database) would support data collection.

Physiotherapy. The workstream group agreed that physiotherapy is an essential part of therapy for bronchiectasis. The workstream group felt that the provision of dedicated respiratory physiotherapy is variable around Scotland, with some areas only having access to physiotherapists through pulmonary rehabilitation services.

Fungal lung disease. There is a national level agreement that people with aspergillus lung disease be seen in the National (UK) Aspergillus Centre at the Wythenshawe Hospital in Manchester. The workstream discussed the perceived increase of prevalence of Aspergillus Lung Disease in Scotland and the long travel times from Scotland to Manchester for people from more rural and remote areas, and those who are most frail. Data is required to understand if fungal lung disease is now sufficiently prevalent in Scotland to require local expertise in each area, with fungal infection multidisciplinary teams including specialist radiologists, infectious diseases consultants, and immunologists (where available).

Chronic Obstructive Pulmonary Disease (COPD)

Symptoms, causes, diagnostics and treatment

Chronic obstructive pulmonary disease (COPD) is the name for a group of lung conditions that cause breathing difficulties, caused by inhalation of toxins, mainly from cigarette smoking.

Symptoms

The main symptoms of COPD are:

- increasing breathlessness, particularly when active
- a persistent chesty cough with phlegm; some people may dismiss this as just a "smoker's cough"
- frequent chest infections
- persistent wheezing

Causes

COPD is largely a preventable condition. The risk of developing it is significantly reduced by not smoking.

Stopping smoking can help prevent further damage to lungs before it starts to cause troublesome symptoms.

COPD includes:

- emphysema – damage to the air sacs in the lungs
- chronic bronchitis – long-term inflammation of the airways .

COPD is a common condition that mainly affects middle-aged or older adults who smoke. Many people don't realise they have it.

The breathing problems tend to get gradually worse over time and can limit normal activities, although treatment can help keep the condition under control.

Treatment

Without treatment, the symptoms usually get slowly worse. There may also be periods when they get suddenly worse, known as a flare-up or exacerbation.

COPD occurs when the lungs become inflamed, damaged and narrowed. The main cause is smoking, although the condition can sometimes affect people who have never smoked.

The likelihood of developing COPD increases the more the individual smokes and the longer they have smoked.

The damage to the lungs caused by COPD is permanent. Only stopping smoking can slow the progression of disease, but some other treatments can be effective in reducing symptoms, exacerbations, and mortality from COPD.

Treatments include:

- stopping smoking - the most important thing to do
- pulmonary rehabilitation – a specialised programme of exercise and education that has been shown to reduce mortality, reduce exacerbation rates, and improve quality of life
- vaccinations, particularly against influenza and pneumococcus
- inhalers and medications, including home oxygen to help make breathing easier, improve exercise capacity, reduce exacerbations
- surgery or a lung transplant, although this is only an option for a very small number of people, COPD remains the commonest indication for lung transplantation, and endobronchial valve/coil treatments are increasingly effective in selected patients.

The COPD workstream raised the following issues with the current diagnostics, management and care.

Pulmonary rehabilitation. The members of the COPD workstream were clear that equitable access to pulmonary rehabilitation across Scotland is the first priority in the management of COPD. Provision of pulmonary rehabilitation is variable across Scotland. There is variation in where it is held, who leads the classes (nurses, physiotherapists, or both), how access is granted (direct primary care access, or through secondary care), and provision of repeat rehabilitation. Accurate data on the supply of, and demand for, pulmonary rehabilitation are essential to improve the provision of pulmonary rehabilitation in Scotland. Collection of data from pulmonary rehabilitation should be standardised across Scotland.

Diagnostics – spirometry. Diagnostic spirometry is a test which measures lung function in a controlled environment. It is carried out in primary and secondary care environments throughout Scotland.

Although spirometry is available both in primary and secondary care environments. The group thought that, in primary care, the test is not available throughout all Health Boards. However, those areas that do provide spirometry, access is generally more rapid, and closer to the person's home.

Primary care spirometry training should be standardised, as well as have a clear quality assurance pathway for non-ARTP (Association for Respiratory Technology & Physiology) accredited practitioners. The group believed that waiting times for spirometry are variable, from few days to 6 weeks or more.

The workstream group members suggested that respiratory diagnostic hubs may be a solution to providing high quality, quality assured spirometry, with skilled interpretation.

Smoking cessation services. The group felt that there is a need for a cohesive national smoking cessation program. Opportunistic smoking cessation advice programs, including targeting people who are staying in hospital or attending out patients appointments have proven to improve quit rates.

Vaccines. Vaccinations are an crucial part of reducing hospitalisations and exacerbations for people with COPD. It was thought that uptake of vaccines is poor in this patient group. The vaccination transformation program, yet

to be fully enacted, instructs regional health boards to provide a co-ordinated Plan to ensure all people who are eligible for influenza and pneumococcal vaccines are given access to those vaccines. A clear Plan of where people can receive vaccinations, including during routine primary and secondary care encounters, and acute admissions, in a more comprehensive and opportunistic manner is a priority.

Specialist Nurses. The workstream group thought that specialised nursing services is varied across the Country and are provided by secondary or primary care. People with COPD highly value contact with specialist COPD nurses. The workstream group thought that it is important that people with COPD have access to specialist nurses. They also thought that it would be beneficial if nurse specialty qualification were clearly defined, as well as a set number of specialist nurses per population of people with COPD.

Idiopathic pulmonary fibrosis, and other forms of pulmonary fibrosis

Symptoms, causes, diagnostics and treatment

Pulmonary fibrosis is a condition in which the lungs become scarred, or thickened: breathing becomes increasingly difficult, then, as the disease progresses, oxygen levels within the blood begin to fall. Idiopathic pulmonary fibrosis (IPF) is the most common of these diseases, but there are a range of others. When this Plan refers to IPF, other forms of pulmonary fibrosis are implied.

Symptoms

The main symptom of IPF is breathlessness. People living with IPF may also experience a persistent cough and may feel tired all the time. Finger clubbing might also be a symptom for some.

Causes

The cause is not clear, but it usually affects people in their 6th and 7th decade and is rare in people under 50. It is more common in men than women, and more common in current or ex-smokers.

Antifibrotic treatments can help reduce the rate at which IPF progresses, but there is currently no treatment that can stop or reverse the fibrosis of the lungs.

In people with IPF, the tiny air sacs in the lungs (alveoli) become damaged and increasingly scarred resulting in stiff, less compliant lungs. The person must work much harder to breathe, perceived as breathlessness. As the lungs become increasingly scarred there is a reduction in the amount of oxygen absorbed into the blood. Over time, this causes damage to the heart, kidneys, and brain. Breathlessness can become very severe, greatly limiting people' exercise capacity and ultimately making them house bound.

The reason this happens is not clear. Idiopathic means the cause is unknown.

IPF has been linked to:

- exposure to certain types of dust, such as metal or wood dust
- viral infections
- a family history of IPF – around 1 in 20 people with IPF has another family member with the condition
- gastro-oesophageal reflux disease (GORD)
- smoking

Diagnostics

If a GP thinks a person could have a lung condition such as IPF, they can refer to a hospital specialist for tests such as:

- breathing (lung function) tests
- blood tests
- a chest X-ray and CT scan
- a lung biopsy, where a small piece of lung tissue is removed during either keyhole surgery, or bronchoscopy (a telescopic camera test into the lungs) so it can be analysed under a microscope

Treatment for IPF

There is currently no cure for IPF, but there are treatments that can help relieve the symptoms and slow down its progression.

Treatments include:

- self-care measures, such as stopping smoking, eating healthily and exercising regularly
- medicines to reduce the rate at which scarring worsens, such as pirfenidone and nintedanib

- breathing oxygen through a mask – this can be done whilst a person is at home or while they're out and about
- exercises and advice to help breathe more easily (pulmonary rehabilitation)
- a lung transplant – this is suitable in a few cases, although donor lungs are rare

The Pulmonary Fibrosis workstream raised the following issues with the current diagnostics, management and care of pulmonary fibrosis

Diagnostics. IPF and other forms of pulmonary fibrosis are rare: a typically sized general practice in Scotland may have only 2 people with IPF, and fewer than 5 with pulmonary fibrosis of any form. Given its rarity, the group believed that there is a need for better awareness of this condition to avoid possible delay in diagnosis. It was highlighted that the work undertaken by the Scottish Access Collaborative shows that primary care access to diagnostic tests, notably high-resolution computed tomography (HRCT) scanning, shortens the person's journeys without increasing demand on investigations. Diagnostic algorithms for IPF should include primary care access to HRCT, and describe pathways for ongoing referral in the case of a positive results. Key to this process is engagement with colleagues in radiology and primary care.

Access to secondary care. There should be a clearly defined referral pathway in place for every centre in Scotland. Larger centres may have pulmonary fibrosis specific clinic and a lead clinician for pulmonary fibrosis; other smaller centres may need to collaborate with other local centres to pool resources and expertise. There should be access to pulmonary fibrosis multidisciplinary meetings (including experts in respiratory medicine, radiology, and specialist nursing), either locally or via remote access to a bigger centre.

Access to anti-fibrotic agents. There is clear evidence that the uptake of anti-fibrotic agents for IPF (specifically) is very variable across the country, with no clear understanding of why this is the case. This warrants further investigation as a priority in this disease area.

Specialist nurses. NICE clinical guideline CG163 recommendation 1.3.3 states
That an interstitial lung disease specialist nurse should be available at all stages of the care pathway to provide information and support to people with idiopathic pulmonary fibrosis and their families and carers with the person's consent.

Specialist nurses may be primary or secondary care based, but they must be sufficiently trained to deal with the specific and generic challenges presented by people with IPF.

There is a masters level nursing module focussed on interstitial lung disease (ILD) available, although there is some uncertainty on how this can be accessed equitably across the country.

Research by the British Lung Foundation in England and Wales shows that people with IPF highly value the input of a specialist IPF nurse, as they provide holistic, person centred, personalised care This includes self-management plans, review of symptoms and lung function, cognitive behavioural therapy, and palliative care.

Palliative care. There is a perception that there is variation in provision of palliative care for non-malignant respiratory illness in Scotland. The newly formed palliative care Managed Clinical Network (MCN) is closely aligned with respiratory MCNs throughout Scotland. Palliative care for people with IPF includes management of breathlessness, anxiety, depression, psychological isolation and desperation, and the provision of palliative oxygen therapy.

Long term oxygen therapy. Oxygen therapy is key in the management of later stage pulmonary fibrosis. The national service agreement for oxygen provision is an example of excellent practice.

Pulmonary Rehabilitation (PR). Pulmonary fibrosis specific PR differs from COPD pulmonary rehabilitation. It is currently unknown how many pulmonary fibrosis specific PR services exist in Scotland and intelligence is required to determine the need for specific

Obstructive Sleep Apnoea Syndrome

Symptoms, causes, diagnostics and treatment

Obstructive sleep apnoea syndrome (OSA) is a relatively common condition where the walls of the pharynx and larynx relax and narrow during sleep, interrupting normal breathing.

This may lead to regularly interrupted sleep, which can have a significant impact on quality of life and increases the risk of developing certain conditions.

Apnoea and hypopnoea

There are 2 types of breathing interruption characteristic of OSA:

- apnoea – where the muscles and soft tissues in the throat relax and collapse sufficiently to cause a total blockage of the airway; it's called an apnoea when the airflow is blocked for 10 seconds or more
- hypopnoea – a partial blockage of the airway that results in an airflow reduction of greater than 50% for 10 seconds or more

People with OSA may experience repeated episodes of apnoea and hypopnoea throughout the night. These events may occur around once every 1 or 2 minutes in severe cases. As many people with OSA experience episodes of both apnoea and hypopnoea, doctors sometimes refer to the condition as obstructive sleep apnoea-hypopnoea syndrome, or OSAHS.

The term "obstructive" distinguishes OSA from rarer forms of sleep apnoea, such as central sleep apnoea, which is caused by the brain not sending signals to the breathing muscles during sleep.

Symptoms

The primary symptom of OSA is daytime somnolence: falling asleep easily during the day.

During an apnoeic episode when oxygen saturations fall sufficiently, the brain awakens the person, bringing them from deep, restorative sleep, into a lighter sleep or wakefulness, during which the airway reopens, and normal breathing, and oxygen saturations, are restored. These repeated sleep interruptions can make the individual feel very tired during the day.

The person usually has no memory of their interrupted breathing, so they may be unaware they have a problem.

It's normal for the muscles and soft tissues in the throat to relax and collapse to some degree while sleeping: most people will experience some apnoeas every night, however in most cases this does not cause significant problems, and the person do not have daytime somnolence.

Causes

In people with OSA, the airway narrows as the result of a number of factors, including:

- being overweight
- OSA is more common in men than in women
- being over 40 years of age
- taking medicines with a sedative effect – such as sleeping tablets or tranquillisers
- alcohol
- smoking
- the menopause (in women)
- having a family history of OSA
- nasal congestion

Treatment

Daytime somnolence due to OSA can be treated effectively:

- lifestyle changes – such as losing excess weight, cutting down on alcohol and sleeping on the side
- using a continuous positive airway pressure (CPAP) device – these devices prevent airway closure during sleep by delivering a continuous supply of pressurised air through a mask
- wearing a mandibular advancement device (MAD) – this gum shield-like device fits around the teeth, holding the jaw and tongue forward to increase the space at the back of the throat during sleep

Surgery may rarely be an option if OSA is thought to be the result of a physical problem that can be corrected surgically, such as an unusual inner neck structure.

The Obstructive Sleep Apnoea Syndrome Workstream Group raised the following issues with the current diagnostics, management and care.

Diagnostics. The group thought that there is variation in practice across Scotland.
A number of Health Boards have a dedicated OSA assessment and treatment units, designed to deal with the prevalence and incidence of OSA within their catchment area. Other areas have Service Level Agreements with larger centres to deal with either the treatment, or assessment and treatment, of people with OSA. Pathways are variable, particularly in centres where diagnostics are carried out locally, but treatment is initiated at a larger centre.

An example of good practice exists where people are seen rapidly by a specialist nursing team for assessment, diagnostics, interpretation of results, and initiation of therapy within 48 hours, with a waiting time within 6 weeks. The workstream felt this pathway may be repeated across Scotland.

Vetting. Referrals for assessment and treatment of OSA make up nearly half of the referrals to respiratory medicine in most centres. The probability of a positive diagnosis varies widely, and most centres have a single pathway for assessment. Many people have a very high probability of OSA, based on their clinical history, whereas others have a very low probability, usually due to lack of significant daytime somnolence, or risk factors. A pathway that allows for variation in assessment due to probability of OSA would be welcomed.

Diagnostic hubs and locality based assessment. The acceptable diagnostic test is agreed to be Limited Polysomnography (LPSG), a sleep test. This technology is now more affordable, and test interpretation more automated, allowing testing to be carried out nearer to the patient, rather than in large hospital centres.

Diagnostic Respiratory Hubs have been suggested as an ideal location for OSA assessment centres, with LPSG available at a local level. Negative studies will reduce the referral to secondary care; positive studies will streamline the access to therapeutics for OSA. A nurse led model of OSA assessment and treatment could be integrated into a diagnostic respiratory hub, negating the need for secondary care involvement.

Machines and consumables. It was highlighted that specialist nurses spend a lot of time dealing with problems caused by machinery, and the consumables associated with the Continuous Positive Airway Pressure (CPAP) therapy. It was suggested that a solution would be to engage with industry that could provide a service where they provide all the equipment, the consumables, etc. A national service level agreement, such as that made for Oxygen therapy, would be beneficial to streamline the delivery of machinery and consumables directly to the patient, freeing up specialist nursing time to focus on assessment and treatment of people with OSA.

Annex B

Summary of Commitments

Commitment 1
We will work with all relevant policy areas to ensure preventative measures are embedded in all aspects of respiratory care.

Commitment 2
We will improve and simplify access to appropriate diagnostic tests for respiratory conditions and explore the use of high quality, consistent spirometry testing and chest & lung CT scans.

Commitment 3
We will support the ongoing work within the Scottish Access Collaborative' disease-specific pathway projects and ensure developments are embedded within wider respiratory policy.

Commitment 4
As part of the Rehabilitation Framework implementation programme, we will ensure everyone with respiratory conditions who would benefit from specialist, general and community rehab is able to access appropriate services and support.

Commitment 5
We will work with people living with respiratory conditions to better understand the barriers to accessing appropriate mental health support; and collaborate with policy and health & social care teams to determine opportunity for improvements.

Commitment 6
We will work with key partners to understand and improve pathways for a good transition from children and young people services to adult respiratory services, and ensure all young people with long term respiratory conditions go through a dedicated respiratory transition service.

Commitment 7
We will work with the NHS, clinicians and the third sector to ensure provision of best practice palliative care for people with a lung condition as they near the end of life and support wider roll out of Anticipatory Care Plans.

Commitment 8
We will work with key stakeholders to help ensure carers of people with respiratory illness are aware of their rights and how to access support.

Commitment 9
We will work in partnership with key stakeholders including the third sector and DHI to ensure people with respiratory conditions have access to tools, resources and information that support them to manage their own condition.

Commitment 10
We will build on the data within the Atlas of Variation and work towards a core respiratory data set, in order to understand areas for improvement.

Commitment 11
We will support wider workforce planning activity to develop innovative, sustainable workforce models within respiratory services.

Commitment 12
As clinical guidelines evolve, we will work with key partners, including NHS Education (NES), to ensure relevant and consistent training is made available to a wider group of healthcare professionals and third sector services, across Scotland.

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