

# **Respiratory Care Action Plan for Scotland**

**(Draft for Consultation)**

**2020-2025**

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## 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 about their patients; streamlining referral pathways; and providing high quality ongoing care for people with chronic respiratory disease.

Pulmonary malignancy is a clinical priority covered by other guidance. Of the other respiratory complaints 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.

***Dr Tom Fardon***  
***Consultant Respiratory Physician***  
***NHS Tayside***

## Executive summary

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

This draft Plan identifies key priorities and sets out why they are important. It is intended to be an enabling document which will continue to evolve, supporting continuous improvement and encouraging people to test new approaches and to share best practice. It is not intended as a replacement of current clinical guidance.

We have developed this draft Plan with the expectation that it will stimulate the evolution of new ideas that can be further tested and evaluated. The draft Plan aims to build on what already works well, challenge the more traditional models in areas that may not be providing the best solutions for people living with a respiratory condition, and introduce innovative ideas to improve health outcomes and equity of access to high quality care.

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

We encourage everyone, clinicians, members of the public, people with a respiratory condition, third sector and others to respond to this consultation.

During the consultation period, we intend to carry out further engagement in order to help shape the Plan further. We will then gather and analyse responses to the consultation. Our aim is to publish the final Respiratory Care Action Plan for Scotland in 2020. We will then work with partners to develop an implementation Plan, to take forward our vision for Respiratory Care in Scotland.

Throughout the draft Plan we have used the term “respiratory community” to mean people living with respiratory conditions, their families and carers, those who provide care and support, practitioners, clinicians, academics, NHS Boards, Integration Authorities, third sector and independent care providers.

Throughout this document we refer to this draft Plan as the “Plan”.

# Chapter One

## Respiratory conditions

Although respiratory condition is a general term used to describe a large group of conditions that impair airways and lungs, this plan is aimed at five specific lung conditions. Other conditions affecting the lungs (for example, cancer and rare diseases) are already included within other Scottish Government strategies<sup>1</sup>.

### What are respiratory conditions?

Respiratory conditions are diseases of the airways and other structures of the lung and are a major contributor to ill-health, disability and premature mortality. The most common conditions are chronic obstructive pulmonary disease (COPD), and asthma.

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

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<sup>2</sup>.

### Impact of respiratory conditions

Many people struggle with chronic respiratory conditions. These conditions have a major impact on their lives and the lives of their families. Some experience loss of time from work or school, and difficulty participating in social activities. Anxiety and depression are common, and are associated with worse quality of life, increased medical symptom reporting, more frequent exacerbations and hospitalisations, prolonged length of hospitalisation, and increased mortality.

We know that respiratory conditions affect people and their families in different ways. We know that for some people and their families a respiratory condition is a life changing diagnosis, affecting the person's ability to live independently, achieve personal ambitions, sustain their personal identity or life roles, work or drive. Any of these factors can cause anxiety, stress and depression for the person and their family/carers, and increase their sense of isolation.

It is also common for people with respiratory conditions to have additional long-term conditions such as hypertension, coronary heart disease, or diabetes.

## **Developing the draft Respiratory Care Action Plan**

The Plan focuses on 5 conditions:

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

These 5 conditions, although not fully comprehensive, cover a wide range of issues facing people with respiratory conditions in Scotland today. Some are unique to specific conditions, some are common to more than one.

Dr Tom Fardon worked with condition specific multidisciplinary groups in order to gather an understanding of the care and support that is currently available, the existing gaps in service provision, as well as identifying examples of good practice and priorities for improvement.

The issues raised at the condition specific workstream meetings are reported in Annex C.

The Plan takes into account inputs and comments from healthcare professionals, policy makers and third sector organisations.

### **Scottish Access Collaborative**

We have also worked across a range of Scottish Government policies. Part of this involved linking up with the work that the Scottish Access Collaboration (the Collaborative)<sup>3</sup> is undertaking.

The Collaborative was established in the autumn of 2017 and is making real progress to reform elective services. The Collaborative includes a focus on a number of challenges including improving referral processes, giving people more choice on when they have return outpatient appointments, and improving service capacity planning. We will continue to work with the Collaborative during the consultation period, and beyond.

The Collaborative is led by Paul Hawkins, Chief Executive of NHS Fife with Professor Derek Bell, Chair of the Academy of Medical Royal Colleges, and is made up of a range of professional bodies including clinical professional groups, patient representatives, clinical and service leaders and Scottish Government officials.

The Collaborative has developed a number of principles which will shape and prioritise the way services are provided in the future.

A key early strand of the Collaborative's work was the delivery of the Speciality Group series of design-led workshops, supported by the Digital Health and Care Institute (DHI), which developed high level mapping of each clinical area to identify

clinically led and person centred sustainable improvements. The ongoing Specialty Group implementation programme is taking forward delivery of these improvements.

### **Scottish Access Collaborative and Respiratory Speciality Group**

Members of the Specialty Group came from 16 specialist areas and 6 different NHS board areas, giving the sub-group both a broad geographic and functional reach.

The first step was to identify common respiratory symptoms, noting their importance. Issues were mapped for each symptom and areas to focus on agreed. 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 know that there is a need for change. People feel treatment is “done to them” and want instead to be partners in their care. This requires support, both for health and social care professionals and individuals, to be able to shift the balance of power to a more equal relationship, good communication, and improvement in how care and support are delivered, if we are to meet the need to provide truly person centred care.

### **Interaction with other Scottish Government policies**

Our Plan sits alongside a wide range of government policy. In particular, this draft Plan should be read alongside tobacco<sup>4</sup>, air quality<sup>5</sup>, immunisation and diet and healthy weight policies<sup>6</sup>.

We seek coherence across a range of other policy areas and we will continue to work collaboratively across the Scottish Government to ensure that appropriate links are made and maintained.

## **Our vision and aims**

This draft Plan outlines a strategic approach to support NHS Boards in the prevention, diagnosis and treatment of respiratory conditions. It also recognises and reflects the approach taken in other Scottish Government strategies and plans.

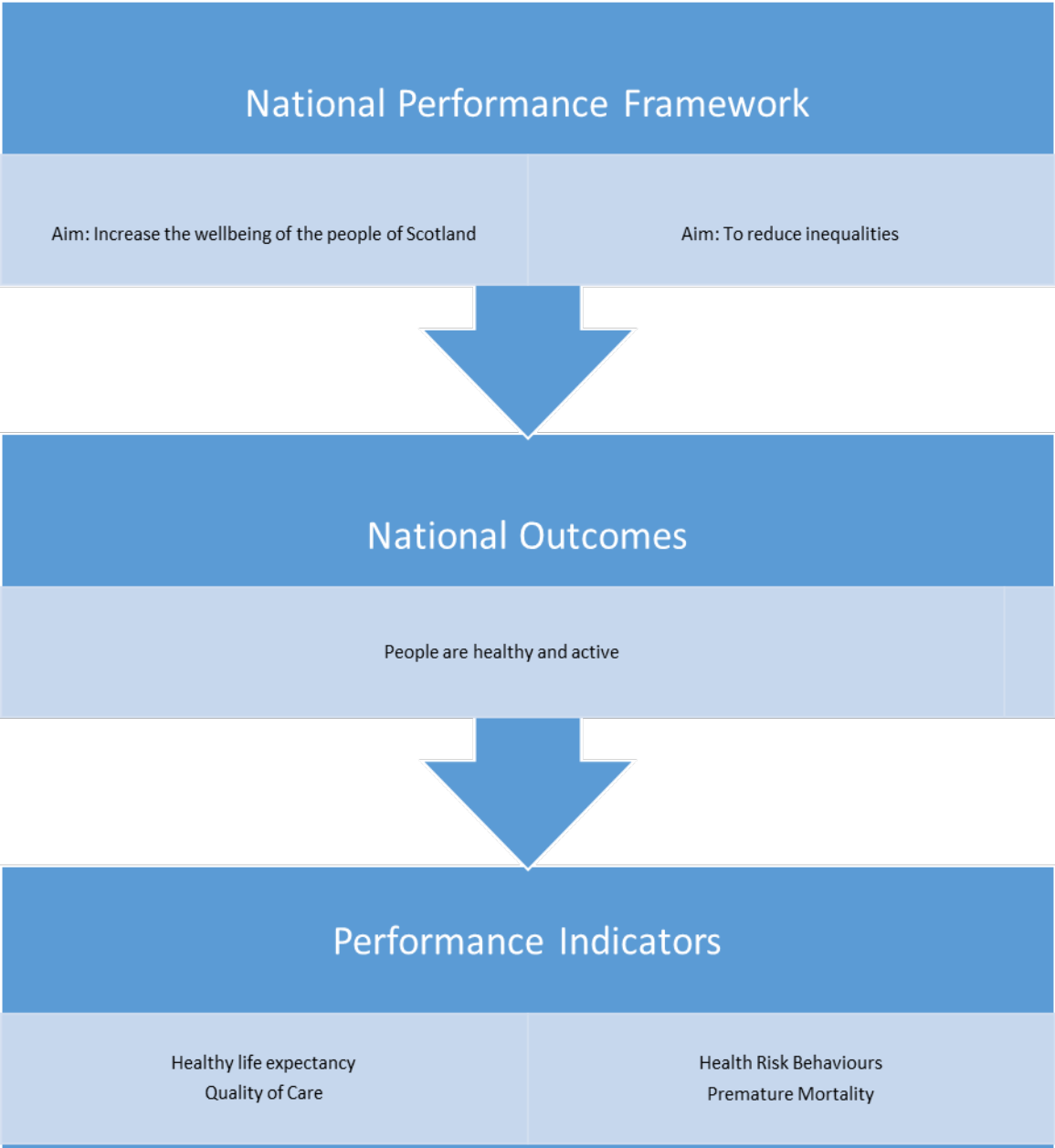
Sitting above all of this is Scotland's National Performance Framework<sup>7</sup>. Two of the aims of the Framework are to increase the wellbeing of people living in Scotland and to reduce inequalities.

The priorities in the Plan will contribute to the National Performance Framework and its outcomes. We will know this by measuring progress against the following performance indicators: Healthy life expectancy, Health risk behaviours, Quality of care experience, Premature Mortality.

### **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.**





## **Our aims**

We will realise our vision by working with national, regional and local services to:

- Support people to manage their condition as appropriate to their needs;
- Develop integrated and co-ordinated models of care and support with the respiratory community;
- Support Health and Social Care Partnerships (HSCP) to embed mainstream models of care that ensure personalised support in every case, and options over the level of control the individual and their family choose to take, in accordance with the Social Care (Self-Directed Support) (Scotland) Act 2013;
- Test and introduce innovative ways of delivering health and social care and support;
- Improve our understanding of the respiratory population in Scotland;
- Improve ways of measuring quality of care outcomes via better data collection and use of outcome measures.

### **Question 1 – Vision and aims**

Do you agree with the overall vision and aims of this draft Plan?

Yes/No/Don't Know

Please expand on your answer if you wish to.

## **Chapter 2**

### **Our Priorities**

**Priority 1 – Prevention**

**Priority 2 – Diagnosis, management and care**

**Priority 3 – Person centred and self-management**

**Priority 4 – Equal access**

**Priority 5 – Workforce**

### **Question 2 – Our Priorities**

Do you think we have included the most important priorities in this draft Plan?

Yes/No/Don't Know

Please expand on your answer if you wish to.

## Priority 1 - Prevention

Preventing respiratory conditions where possible, and reducing the risk of their development, means reducing or avoiding exposure to common risk factors.

The biggest risk factors include tobacco, air quality and respiratory infections.

The Scottish Government has set out ambitious aims through our strategies and Plans to combat the health implications in respect of smoking, clean air, healthy weight and the importance of vaccinations, as outlined below.

## Tobacco

Smoking is the primary preventable cause of ill-health and premature death. Each year, tobacco use is associated with 100,000 smoking attributable hospital admissions and 9,000 smoking attributable deaths per year in Scotland<sup>8</sup>; a fifth of all deaths.

The Scottish Government's Tobacco Control action Plan, published in June 2018, sets out our 5-year Plan to address the ongoing harms which smoking causes in Scotland. We are determined to tackle the inequalities of smoking, to prevent the uptake of smoking among young people and to provide the best possible support for those people who want to give up.

We 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.

As well as reducing the levels of people taking up smoking we are achieving a year-on-year increase in the proportion giving up smoking. Scotland's NHS stop-smoking services were commended in the July 2018 Cancer Research UK report as the only services in the UK to tackle inequalities, focussing efforts in more deprived communities where prevalence is higher and the impact of smoking greater. This is being achieved by giving health boards and integration authorities specific targets for supporting people in our most deprived communities.

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. Quit Your Way provides a uniform service across Scotland with smokers offered specialist support and advice coupled with free nicotine replacement treatments such as medication, patches, gum etc. The re-brand was supported by the successful national TV and radio campaign 'Get Through 72' which focussed on the critical first three days of a quit attempt.

The health impact of smoking, not only in relation to respiratory conditions, cannot be underestimated. Therefore it is important that the commitments and actions already being undertaken in wider Scottish Government policies to combat smoking must be reflected in this Plan. Whilst this draft Plan contains specific commitments in relation to respiratory conditions, we must not lose sight of broader aims.

### **Air quality**

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 enjoys a high level of air quality.

We have already 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 has been published<sup>9</sup>.

### **Flu vaccination**

The majority of flu vaccines in Scotland are currently provided by GPs. While there are pilots planned for flu vaccination delivery in some areas, GPs remain responsible for providing flu vaccinations until such time as the transformation programme can be transferred safely to the ownership of the Health Board. Local communications will inform parents/ patients in pilot areas about the arrangements for receiving the vaccination.

## **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.

Given the complexity of the problem we face, the Plan is wide-ranging, but its central aim is to make it much easier for everyone across Scotland to eat well and have a healthy weight.

Our 'Diet and Healthy Weight Delivery Plan' aims to significantly reduce diet-related health inequalities by taking action at a population-wide level that will benefit everyone in Scotland, and delivering targeted and tailored support specifically to those individuals, children and families who need it most.

## Priority 2 - Diagnosis, management and care

### Diagnosis

Early and accurate diagnosis of respiratory conditions is critical, as any treatment and support can begin before the disease has progressed. People are better placed to manage their condition and to take positive choices.

Late diagnosis, under-diagnosis and misdiagnosis can have a large impact on health outcomes including quality and length of life.

### Early and correct diagnosis of respiratory conditions are a priority

To diagnose respiratory conditions correctly and provide the best care possible, healthcare professionals need ongoing education on these conditions, including in primary care, and those in rural and remote areas.

#### Commitment 1

We will support respiratory health training and education for healthcare professionals by working with NHS Education Scotland and other partners to ensure that education and training on respiratory conditions is delivered/is available to healthcare professionals.

We will support education to be available in a variety of formats to optimise accessibility.

#### Commitment 2

We will improve equitable access to evidence based diagnostic tests by working with partners to reduce variation in the quality of spirometry testing across the Country and design pathways for complex respiratory function testing.

#### Commitment 3

We will support consistent disease specific pathways and work with the sector to ensure they are embedded in the health services and partners.

### Question 3 - Early and correct diagnosis of respiratory conditions are a priority

Do you agree with commitments 1, 2 and 3?

Yes/No/Don't Know

Please expand on your answer if you wish to.

## Management and care

Several different healthcare professionals are involved in the care of people with respiratory conditions. Healthcare professionals need access to easy to use evidence-based clinical practice guidelines and care pathways for respiratory conditions in order to provide consistent best-practice care.

Pulmonary rehabilitation offers a structured exercise and education programme designed for those with respiratory conditions. Pulmonary rehabilitation encourages increased physical activity within the person's limitations. It also offers advice about drugs and how to use them, pacing activities, eating, weight management and psychological issues.

90% of people who complete the programme experience improved exercise capacity or increased quality of life<sup>10</sup>.

However, Chest Heart and Stroke Scotland (CHSS) estimates that just between 2% and 21% of those who might benefit are being referred to pulmonary rehabilitation<sup>11</sup>.

We expect NHS Boards to provide access to accredited pulmonary rehabilitation programs based on current clinical guidelines<sup>12</sup>.

It is imperative that we expand pulmonary rehabilitation services over the next 5 years. This will enable people to manage their health better and reduce costs.

### **Commitment 4**

We will support NHS Boards to increase access to pulmonary rehabilitation. We will design pulmonary rehabilitation pathways based on examples of best practice and test them in areas where improvement is required. We will look at ways of providing support to a wider group of people with rehabilitation and self-management support.

### **Question 4 - Increase access to pulmonary rehabilitation**

Do you agree with commitment 4?

Yes/No/Don't Know

Please expand on your answer if you wish to.



## **Mental health Support**

Coming to terms with a diagnosis of a respiratory condition can affect mental health and wellbeing. People with a diagnosis of a respiratory illness have different levels of need for mental health support.

### **Commitment 5**

We will work with NHS Boards, clinicians and third sector to promote good practice and reduce variation in the quality of mental health support access across the Country.

### **Question 5 – Mental health support**

Do you agree with commitment 5?

Yes/No/Don't Know

Please expand on your answer if you wish to.

## **Transition from child and young people services to adult services**

One of the most important aspects in the management of asthma is the period of transition from childhood to adulthood. Healthcare teams need to support patients and carers in getting ready to move from children's healthcare to adult healthcare.

A good asthma care transition plan should give plenty of time to prepare for this transition.

### **Commitment 6**

We will work with key partners to develop policies and procedures for a good transition from children and young people services to adult services for asthma.

### **Question 6 - Transition from child and young people services to adult services**

Do you agree with commitment 6?

Yes/No/Don't Know

Please expand on your answer if you wish to.

## **Palliative care**

A palliative approach is central to best-practice end of life care. In some cases it should begin when a time-limiting disease is diagnosed, with increasing input as required.

The disease progression in some lung conditions is unpredictable. It should be recognised that active disease management and a palliative approach are complementary, not mutually exclusive, the introduction of palliative measures does not preclude active management, rather there is a continuum of care that progresses towards a more end of life approach as the disease progresses.

Increasing access to specialist services is important, alongside training and education of all health professionals involved in respiratory conditions in palliative care principles and practice including anticipatory care planning, discussions around attempt at resuscitation, and escalation of care decisions.

### **Commitment 7**

We will work with NHS Boards, clinicians and the third sector to reduce inconsistencies in the provision of best practice palliative care for people with a lung condition as they near the end of life.

### **Question 7 – Palliative care**

Do you agree with commitment 7?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **Priority 3 – Person centred and self-management**

The important role of self-management for people with chronic conditions is well established.

By supporting people with respiratory conditions to increase their knowledge and confidence in self-management practices, we can empower them to play an active role in their own health care and better manage their condition.

To do this, evidence-based tools, information and support services that allow for shared decision making between people with respiratory conditions and healthcare professionals are critical. Innovative technologies also have a role to play in supporting people to be actively involved in their healthcare.

#### **Anticipatory Care Plans**

It is also very important to support people in planning ahead and discussing their wishes for future care. Anticipatory Care Plans (ACP)<sup>13</sup> can benefit people with living with respiratory conditions and can also be beneficial to individuals towards the end of their life.

A national programme to support the implementation of Anticipatory Care concluded in June 2018; an anticipatory care Planning approach is now being embedded across all areas of work in Healthcare Improvement Scotland and the Living Well in Communities Programme.

#### **Unpaid carers**

Unpaid carers play a key role in supporting their loved ones.

The Carers (Scotland) Act 2016 sets out a range of measures intended to improve the support given to carers. This includes the introduction of new duties on local authorities to support carers who are assessed as needing support and who meet eligibility criteria<sup>14</sup>.

### **Commitment 8**

We will provide tools, and information for people with lung conditions to support effective self-management practices by:

- working with NHS Inform, and stakeholders across the Respiratory Community to improve the range of information available on respiratory conditions;
- supporting further development of a local Information System for Scotland (ALISS) as a national resource for sign-posting people with respiratory conditions to care and support;
- supporting health literacy to ensure that people have the knowledge, skills, understanding and confidence to use health information, to be active partners in their care, and to navigate health and social care systems;
- working with partners to increase access to community-based support for an effective self-management that complements clinical management and care.

### **Commitment 9**

Support innovative technologies to enable people to be actively involved in their respiratory health.

### **Commitment 10**

Support unpaid carers accessing appropriate information and support their health and wellbeing.

### **Question 8 – Person centred and self-management**

Do you agree with commitment 8, 9 and 10?

Yes/No/Don't Know

Please expand on your answer if you wish to.

## Priority 4 – Equal Access

We know that the current model of primary, secondary and tertiary care works well for some of the respiratory conditions as it allows people to be referred to specialist teams to benefit from appropriate care, therapies and medicines.

However, there are instances where there are barriers to people accessing care and support when and where they need it.

We value the critical role of third sector organisations as key partners in developing, delivering and trialling new services and look to actively support them in creating a sustainable environment, particularly in areas where these organisations may be best placed to deliver services and support. We will also look to actively support third sector organisations as key partners by striving to create a sustainable environment for the care and support they provide.

We know that incidence and mortality rates of chronic diseases are higher in disadvantaged groups and areas of social deprivation, where there is often higher smoking incidence, exposure to higher levels of air pollution, poor housing conditions and exposure to occupational hazards.

This Plan is focused on the delivery of best care for all. Particular focus is needed in supporting people that experience barriers to accessing the appropriate care, such as rural and remote communities, culturally and linguistically diverse groups, protected characteristic and socioeconomically disadvantaged people.

### **Realistic medicine**

Tackling unwarranted variation is essential to improving outcomes derived from healthcare across Scotland. Unwarranted variation is variation in healthcare that cannot be explained by need, or by explicit patient or population preferences. We need to ensure the prevention of harm and waste from overuse and overtreatment, freeing up resources currently used without benefit to clinical outcomes in order to address under-provision of care.

There are a number of initiatives underway that aim to tackle unwarranted variation. For example, the Scottish Atlas of Healthcare Variation aims to highlight geographical variation in the provision of health services and associated health outcomes. It is designed to facilitate discussion and raise questions about why differences exist and promote quality improvement through the conversation. The Scottish Atlas of Healthcare Variation is an important tool to contribute to eliminating unwarranted variation, realising Realistic Medicine and support reducing harm and waste within the health service. The tool is designed to highlight variation and no judgement on the performance or inferences on quality of care of one geographical area against another should be concluded<sup>15</sup>.

We will engage with clinicians and patients to identify which areas to add to the Atlas to help ensure that it reflects the needs of the population, is relevant to clinicians and evolves with innovation.

Variation in care is not confined to health services. We also heard about care and support services not being accessible to people in neighbouring localities because of partnership boundaries, differences in funding essential equipment, and lack of access to therapy services due to place of residence. We need to remove barriers to improve access to care and support so that people can move easily between acute and community, and move in and out of services as appropriate to their needs, and at the right time.

### **Commitment 11**

We will work with the Scottish Atlas of Variation Group to explore developing an Atlas on respiratory conditions.

### **Question 9 – Equal access**

Do you agree with commitment 11?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **Data**

High quality data is important to the NHS as it can lead to improvements in care and safety. Quality data plays a role in improving services and decision making, as well as being able to identify trends and patterns, draw comparisons, predict future events and outcomes, and evaluate services.

### **Commitment 12**

We will work with NHS Information Services Division and others to:

- understand the gaps in prevalence, and how best to improve the data;
- enhance capture of already routine collected data;
- further develop systems and processes that support service planning and workforce development based on this information;
- explore the feasibility of developing a national reporting framework that includes key performance indicators for respiratory care and support and measures improvements in care and support.

### **Question 10 – Data**

Do you agree with commitment 12?

Yes/No/Don't Know

Please expand on your answer if you wish to.

## Priority 5 - Workforce

The delivery of joined up and holistic services require us to think more widely about workforce and those who support the health and wellbeing of people with respiratory conditions.

A number of people experience multiple morbidity. Care coordination is essential to reduce multiple appointments where possible to improve experience and outcomes.

The NHS is the biggest employer in Europe, and the world's largest employer of highly skilled professionals. But our staff are feeling the strain.

Care workers, practitioners and professionals are a huge asset to health and social care and support, therefore it is important to support them in their current roles and in developing new roles.

### **Medical staff**

Medical training is managed at a UK level; the Shape of Training review proposed an important evolution in the development of specialties and their role within provision of healthcare, particularly in the acute sector.

Innovative ways of encouraging applications at consultant level need to be considered. This need not be financially driven - improving study leave provision and training budgets may be one way to enhance the attractiveness of working in Scotland.

### **Nursing staff**

The diversity of the specialist respiratory nurse role across Scotland is not underestimated. This group are open to the challenges associated with supporting a variety of respiratory condition and at times in the rurality of some areas of Scotland.

The integrated community nursing teams which include district nurses, general practice nurses, care home nurses, specialist community nurses and prison health nurses, play a key role in supporting people with respiratory conditions, anticipating care needs, preventing exacerbations through early intervention, supporting self-management and providing palliative and end of life care at home or in a community setting.

Areas where disease treatments are developing, including the introduction of biologic therapies in asthma mean the requirement for people to have more support, education and ongoing follow up all of which the specialist nurse teams can provide.



The Scottish Government's Transforming Nursing, Midwifery and Health Professions (NMaHP) Programme's aim is to ensure nationally consistent, sustainable and progressive NMaHP roles and career pathways, which will see an appropriately skilled workforce contributing to new models of care delivery. The Transforming NMaHP Roles Programme aims to support shifting the balance of care, reducing unscheduled care, unnecessary admissions, supporting people to be at home and the thereafter prevention and anticipatory care. As part of this programme the role and education of Clinical Nurse Specialists is being reviewed and a report outlining this work will be published in spring/summer 2020.

### **Commitment 13**

We will support a programme of innovation and the development of a phased approach to implementation where emerging evidence supports changing models of workforce, such as testing new roles of Advanced Practice for nurses.

### **Question 11 – Workforce**

Do you agree with commitment 13?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **Wider workforce**

It would be helpful for staff working in services such as other medical specialties, community teams, or care homes to receive training in understanding the needs of people with respiratory conditions and this should be available.

There is a need to develop guidance on the use of equipment and interventions by appropriately trained staff.

We support the critical role of third sector organisations in providing services and support. There needs to be consideration as to the sustainability of this workforce, while still recognising the independence of the sector.

Employers are responsible for ensuring their staff have the skills and knowledge to carry out their roles. This responsibility is set out in the Codes of Practice for Social Service Workers and Employers<sup>16</sup> and the Care Inspectorate use the codes in their inspections of services. The National Health and Social Care Standards are also relevant, in setting out what a person can expect from their service provider.

Part 2 of the National Health and Social Care Workforce Plan: Part 2 - a framework for improving workforce planning for social care in Scotland proposes the development of a Framework for Practice in Social Care<sup>17</sup>. This is being led by the Scottish Social Services Council, and will work with stakeholders to consider how such a framework will contribute to ensuring that there are clear routes identified that reflect the development of appropriate expertise in the social services workforce, who provide personal care and support for people at home or in a care setting alongside other professionals.

**Commitment 14**

We will work with stakeholders, in the context of the work taking place under the National Health and Social Care Workforce Plan, to explore how best to further support the development of appropriate expertise in the health and social care and support workforce for those working with people with respiratory conditions.

**Commitment 15**

We will discuss a national or regional approach to workforce planning with stakeholders, to test the extension of existing workforce planning tools and their application to the wider respiratory workforce in Integration Authorities and NHS Boards.

**Question 12 – Wider workforce**

Do you agree with commitment 14 and 15?

Yes/No/Don't Know

Please expand on your answer if you wish to.

## **Partial Equality Impact Assessment (EQIA)**

The Equalities Impact Assessment aims to ensure that any new Scottish Government policies or legislation help promote opportunities where possible for a range of equalities groups and at the very least avoid any discrimination or other unfair treatment of any particular groups of individuals, based on, for example, their gender, race, religion or disability.

We do not feel that the proposals in this consultation would be likely in most cases to impact on individuals in any equalities group differently from others, although there may also be some implications for some people from minority ethnic groups if they do not have a good understanding of English, as well as those with visual or hearing impairments.

We would be grateful for your views on any equalities impacts to ensure that they can be fully considered as part of the Impact Assessment.

### **Question 13 - EQIA**

Do you think there are particular impacts or implications for any equalities groups from any of the commitments in this consultation, either positive or negative?

Yes/No/Don't Know

Please expand on your answer if you wish to.

In the question above, equalities groups should be taken to mean any different impacts the proposals might have on any particular groups of people based on their:  
age  
disability  
gender reassignment  
race  
religion or belief  
sex, or sexual orientation

## **Implementation**

We will consult on this draft Plan to ensure there is wide support for our aims. We want to hear the views of a wide range of stakeholders on our proposals, the priorities, implementation, and - looking ahead - what more should be done.

Responses to the consultation will be analysed and used as part of the decision-making process, along with a range of other available information and evidence. We will publish a report of this analysis.

This report will help shape the final content of the Respiratory Care Action Plan.

We will then work with partners to develop an implementation plan, to take forward our vision for Respiratory Care in Scotland over a 5-year period.

Having worked with the respiratory community to identify the priorities, the expectation is that over the coming years NHS Boards will commit themselves to implementing a programme of work to improve the quality of care and outcomes within these identified priority areas.

An Implementation Lead will be appointed to support Scottish Government, NHS Boards and integrated authorities in working together, develop local Plans for their relevant populations and agree on appropriate actions, targets and timeframes.

## Summary of commitments

### Commitment 1

We will support respiratory health training and education for healthcare professionals by working with NHS Education Scotland and other partners to ensure that education and training on respiratory conditions is delivered/is available to healthcare professionals.

We will support education to be available in a variety of formats to optimise accessibility.

### Commitment 2

We will improve equitable access to evidence based diagnostic tests by working with partners to reduce variation in the quality of spirometry testing across the Country and design pathways for complex respiratory function testing.

### Commitment 3

We will support consistent disease specific pathways and work with the sector to ensure they are embedded in the health services and partners.

### Commitment 4

We will support NHS Boards to increase access to pulmonary rehabilitation. We will design pulmonary rehabilitation pathways based on examples of best practice and test them in areas where improvement is required. We will look at ways of providing support to a wider group of people with rehabilitation and self-management support.

### Commitment 5

We will work with NHS Boards, clinicians and third sector to promote good practice and reduce variation in the quality of mental health support access across the Country.

### Commitment 6

We will work with key partners to develop policies and procedures for a good transition from children and young people services to adult services for asthma.

### Commitment 7

We will work with NHS Boards, clinicians and the third sector to reduce inconsistencies in the provision of best practice palliative care for people with a lung condition as they near the end of life.

## **Commitment 8**

We will provide tools, and information for people with lung conditions to support effective self-management practices by:

- working with NHS Inform, and stakeholders across the Respiratory Community to improve the range of information available on respiratory conditions;
- supporting further development of a local Information System for Scotland (ALISS) as a national resource for sign-posting people with respiratory conditions to care and support;
- supporting health literacy to ensure that people have the knowledge, skills, understanding and confidence to use health information, to be active partners in their care, and to navigate health and social care systems;
- working with partners to increase access to community-based support for an effective self-management that complements clinical management and care.

## **Commitment 9**

Support innovative technologies to enable people to be actively involved in their respiratory health.

## **Commitment 10**

Support unpaid carers accessing appropriate information and support their health and wellbeing.

## **Commitment 11**

We will work with the Scottish Atlas of Variation Group to explore developing an Atlas on respiratory conditions.

## **Commitment 12**

We will work with NHS Information Services Division and others to:

- understand the gaps in prevalence, and how best to improve the data;
- enhance capture of already routine collected data;
- further develop systems and processes that support service planning and workforce development based on this information;
- explore the feasibility of developing a national reporting framework that includes key performance indicators for respiratory care and support and measures improvements in care and support.

## **Commitment 13**

We will support a programme of innovation and the development of a phased approach to implementation where emerging evidence supports changing models of workforce, such as testing new roles of Advanced Practice for nurses.

**Commitment 14**

We will work with stakeholders, in the context of the work taking place under the National Health and Social Care Workforce Plan, to explore how best to further support the development of appropriate expertise in the health and social care and support workforce for those working with people with respiratory conditions.

**Commitment 15**

We will discuss a national or regional approach to workforce planning with stakeholders, to test the extension of existing workforce planning tools and their application to the wider respiratory workforce in Integration Authorities and NHS Boards.



## List of questions

### **Question 1 – Vision and aims**

Do you agree with the overall vision and aims of this draft Plan?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **Question 2 – Our Priorities**

Do you think we have included the most important priorities in this draft Plan?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **Question 3 - Early and correct diagnosis of respiratory conditions are a priority**

Do you agree with commitments 1, 2 and 3?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **Question 4 - Increase access to pulmonary rehabilitation**

Do you agree with commitment 4?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **Question 5 – Mental health support**

Do you agree with commitment 5?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **Question 6 - Transition from child and young people services to adult services**

Do you agree with commitment 6?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **Question 7 – Palliative care**

Do you agree with commitment 7?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **Question 8 – Person centred and self-management**

Do you agree with commitment 8, 9 and 10?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **Question 9 – Equal access**

Do you agree with commitment 11?

Yes/No/Don't Know

Please expand on your answer if you wish to.

**Question 10 – Data**

Do you agree with commitment 12?

Yes/No/Don't Know

Please expand on your answer if you wish to.

**Question 11 – Workforce**

Do you agree with commitment 13?

Yes/No/Don't Know

Please expand on your answer if you wish to.

**Question 12 – Wider workforce**

Do you agree with commitment 14 and 15?

Yes/No/Don't Know

Please expand on your answer if you wish to.

**Question 13 - EQIA**

Do you think there are particular impacts or implications for any equalities groups from any of the commitments in this consultation, either positive or negative?

Yes/No/Don't Know

Please expand on your answer if you wish to.

### **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 throughout 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 patient 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 6<sup>th</sup> and 7<sup>th</sup> 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's 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

## Diagnosics

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**

**Diagnosics.** 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.

**Glossary**

Getting it Right for Every Child	Supports families by making sure children and young people can receive the right help, at the right time, from the right people. The aim is to help them to grow up feeling loved, safe and respected so that they can realise their full potential.
Healthcare Improvement Scotland	Provides assurance to the people of Scotland about the quality of care within a health setting. Its functions include the delivery of improvement support, quality assurance (through inspections and reviews), supporting the engagement of people and communities, and the provision of evidence including advice, standards and guidelines.
Information Services Division	Division of National Services Scotland, part of NHS Scotland. ISD provides health information, health intelligence, statistical services and advice that support the NHS in progressing quality improvement in health and care and facilitates robust planning and decision making.
Primary Care	Refers to the services provided by health professionals in either clinics and practices, or sometimes in peoples' homes. Primary care is normally the first point of contact with the NHS. Within primary care there are four practitioner services: Medical i.e. General Practitioners (GPs) - Dental - Pharmaceutical and - Optical. People may encounter a wide range of different professions within their GP practice or health centre including nurses, physiotherapists, podiatrists.
Secondary Care	Mainly hospital-based health care provision (often referred to as 'acute care'). Services range from emergency care (via Accident & Emergency) to non-emergency treatment, usually through outpatient departments or elective treatment.
Tertiary Care	The provision of specialist services for people with an existing disease, which requires higher levels of expertise and support services. Tertiary care services are usually provided in a limited number of locations around the country and some services are so specialised that they may only be provided on a national basis e.g. liver transplantation. There are also some services, which are commissioned from the other parts of the UK on behalf of all health boards, for

	example, paediatric heart transplants (National Services Division, 2016).
World Health Organisation	Primary role is to direct and coordinate international health within the United Nations system. Main areas of work are health systems; health through the life-course; non-communicable and communicable diseases; preparedness, surveillance and response; and corporate services.

## Responding to this Consultation

We are inviting responses to this consultation by **03 APRIL 2020**.

Please respond to this consultation using the Scottish Government's consultation hub, Citizen Space (<http://consult.gov.scot>). Access and respond to this consultation online at [<https://consult.gov.scot/healthcare-quality-and-improvement/respiratory-care-action-plan>]. You can save and return to your responses while the consultation is still open. Please ensure that consultation responses are submitted before the closing date of **03 APRIL 2020**.

If you are unable to respond using our consultation hub, please complete the Respondent Information Form to:

Clinical Priorities  
Scottish Government  
Ground East Rear  
St Andrews House; Regent Road  
Edinburgh; EH1 3DG

## Handling your response

If you respond using the consultation hub, you will be directed to the About You page before submitting your response. Please indicate how you wish your response to be handled and, in particular, whether you are content for your response to be published. If you ask for your response not to be published, we will regard it as confidential, and we will treat it accordingly.

All respondents should be aware that the Scottish Government is subject to the provisions of the Freedom of Information (Scotland) Act 2002 and would therefore have to consider any request made to it under the Act for information relating to responses made to this consultation exercise.

If you are unable to respond via Citizen Space, please complete and return the Respondent Information Form included in this document.

To find out how we handle your personal data, please see our privacy policy: <https://beta.gov.scot/privacy/>

## Next steps in the process

Where respondents have given permission for their response to be made public, and after we have checked that they contain no potentially defamatory material, responses will be made available to the public at <http://consult.gov.scot>. If you use the consultation hub to respond, you will receive a copy of your response via email.

Following the closing date, all responses will be analysed and considered along with any other available evidence to help us. Responses will be published where we have been given permission to do so. An analysis report will also be made available.

### **Comments and complaints**

If you have any comments about how this consultation exercise has been conducted, please send them to the contact address above or at [Clinical.Priorities@gov.scot](mailto:Clinical.Priorities@gov.scot).

### **Scottish Government consultation process**

Consultation is an essential part of the policymaking process. It gives us the opportunity to consider your opinion and expertise on a proposed area of work.

You can find all our consultations online: <http://consult.gov.scot>. Each consultation details the issues under consideration, as well as a way for you to give us your views, either online, by email or by post.

Responses will be analysed and used as part of the decision making process, along with a range of other available information and evidence. We will publish a report of this analysis for every consultation. Depending on the nature of the consultation exercise the responses received may:

- indicate the need for policy development or review
- inform the development of a particular policy
- help decisions to be made between alternative policy proposals
- be used to finalise legislation before it is implemented

While details of particular circumstances described in a response to a consultation exercise may usefully inform the policy process, consultation exercises cannot address individual concerns and comments, which should be directed to the relevant public body.



**Title: Draft Respiratory Care Action Plan for Scotland**

**RESPONDENT INFORMATION FORM**

**Please Note** this form **must** be completed and returned with your response.

To find out how we handle your personal data, please see our privacy policy:  
<https://beta.gov.scot/privacy/>

Are you responding as an individual or an organisation?

- Individual
- Organisation

Full name or organisation's name

Phone number

Address

Postcode

Email

The Scottish Government would like your permission to publish your consultation response. Please indicate your publishing preference:

- Publish response with name
- Publish response only (without name)

**Information for organisations:**

The option 'Publish response only (without name)' is available for individual respondents only. If this option is selected, the organisation name will still be published.

If you choose the option 'Do not publish response', your organisation name may still be listed as having responded to the consultation in, for example, the analysis report.

Do not publish response

We will share your response internally with other Scottish Government policy teams who may be addressing the issues you discuss. They may wish to contact you again in the future, but we require your permission to do so. Are you content for Scottish Government to contact you again in relation to this consultation exercise?

Yes

No

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