Department of
Health
An Roinn Sláinte
Männystrie O Poustie
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SERVICE FRAMEWORK FOR RESPIRATORY HEALTH AND WELLBEING

Easy Access Version

December 2016

SERVICE FRAMEWORK FOR RESPIRATORY HEALTH AND WELLBEING

INTRODUCTION

Welcome to the easy access version of the Service Framework for Respiratory Health and Wellbeing.

It sets out what you can expect from the Health and Social Care (HSC) services in Northern Ireland if you suffer from or you care for someone suffering from a respiratory disease.

The full document runs to almost 300 pages. You can get a copy by using the contact information at the end of this document.

This version is for people with little or no medical knowledge.

We explain the names of diseases and other specialist terms highlighted in bold type in the glossary.

We also explain the organisations mentioned under the headings ‘Who is responsible for making sure it happens?’

Often you will see percentage targets for meeting the Service Framework’s objectives. You may wonder why we set targets at certain percentages, such as 90, 70 or even 60%. It’s simply because it is much better to fix a realistic target and achieve it, rather than set the bar too high and fail.

Ten standards are marked with this symbol:

A GENERIC STANDARD ✓

This means the standard is general and has health and social care messages for everyone, not just for people with respiratory disease.

The Service Frameworks have the potential to transform health and social care in Northern Ireland.

Contents

STANDARDS

There are a total of 56 Standards in this Service Framework. They are split up into two groups – Generic Standards and Specific Standards. Generic Standards simply means that these standards are included in all the Service Frameworks, not just this one. Specific Standards are those standards which only apply to Respiratory Services.

Generic Standards

There are 10 standards which are included in all Service Frameworks because they apply to all HSC professionals and service users, regardless of their health condition or social grouping. These are called generic standards and they include:

- communication;
- involvement;
- independent advocacy;
- carers;
- healthy eating;
- physical activity;
- smoking cessation;
- alcohol;
- safeguarding; and
- palliative care

These generic standards reinforce the holistic approach to health and social care improvement and reflect the importance of health promotion in preventing medical or social care issues occurring in the first place. Their inclusion ensures:

- equity of opportunity for all;
- the communication of consistent messages to service users and providers of HSC; and
- a consistent approach on the design and delivery of services

Standards 1 to 4

The first 4 Generic Standards focus on communication and patient involvement

Who is responsible for making sure they are done?

- HSC Board
- HSC Trusts
- Primary Care
- The Public Health Agency

#1 Communication

Everyone delivering health and social care should communicate effectively with patients, clients, carers and the public.

What are we trying to achieve?

We want to make sure everyone working in the HSC communicates well with everyone using HSC services.

Why is it important?

As well as keeping everyone clear and well informed, good communication has a big impact on things like preventing disease and the management of long-term conditions.

#2 Involvement

All patients, clients, carers and the public should have opportunities to get involved in the planning, delivery and monitoring of the care they receive.

What are we trying to achieve?
We want to make sure that all patients, carers and the public get involved with their care.

Why is it important?
Research shows that involving patients and the public in health and social care is better for patients, helps communication and improves outcomes of care.

#3 Independent advocacy

Anyone using Health and Social Care services should be able to get an **independent advocacy** service if they need it. This applies to carers too.

What are we trying to achieve?
We want to provide independent advocacy services so people have someone on their side making sure they have more control over their health and social care.

Why is it important?
Independent advocacy can make a real difference to people's lives by allowing HSC users and their families to express their views and wishes.

#4 Identifying and supporting carers

All Health and Social Care staff should identify carers (whether they are parents, family members, siblings or friends) at the earliest opportunity so they can work in partnership with them and make sure they have the support they need.

What are we trying to achieve?
We want to recognise carers as individuals in their own right and as key partners in providing care and support, so that they feel valued and able to get the support they need.

Why is it important?

Carers are key partners in the provision of health and social care. Involving carers in the planning, delivery and monitoring of services improves outcomes for the carer and cared for person.

Standards 5 to 8

The next group of 4 Generic Standards focus on how we can stop people from getting sick in the first place and

Who is responsible for making sure they are done?

- HSC Board
- HSC Trusts
- Primary Care
- The Public Health Agency
- Patient and Client Council
- Regulation and Quality Improvement Authority

#5 Healthy eating

All Health and Social Care staff, as appropriate, should give relevant healthy eating advice and support to all Health and Social Care users.

What are we trying to achieve?

We want to make sure that users of Health and Social Care services, where appropriate, get the right healthy eating advice and support.

Why is it important?

Evidence shows that eating a well-balanced diet can help prevent diseases linked to being overweight and can help people to be healthier and feel better.

6 Physical activity

All relevant Health and Social Care staff should give support and advice on appropriate levels of physical activity.

What are we trying to achieve?

We want to ensure that users of Health and Social Care services get good advice and support for physical activity to promote good health.

Why is it important?

Physical activity promotes good health and helps prevent disease

7 Smoking

All relevant Health and Social Care staff should advise people who smoke to stop. They should know about **smoking cessation** services and direct smokers to them.

What are we trying to achieve?

We want people who are ready to stop smoking to get help through stop smoking services in a choice of settings.

Why is it important?

Smoking is a major health hazard and one of the main risk factors for many types of cancer.

#8 Alcohol

All relevant Health and Social Care staff should provide support and advice on recommended levels of alcohol consumption.

What are we trying to achieve?

We want to make sure that people who drink harmful amounts are aware of the dangers of alcohol and get the right advice at the right time.

Why is it important?

Drinking too much alcohol is associated with many diseases. There are also links between too much alcohol and injuries and violence.

Standard 09

A GENERIC STANDARD

Safeguarding people

All Health and Social Care staff and anyone providing services on their behalf should make sure that people of all ages are safe from harm through abuse, exploitation or neglect.

How we know it's working

- By March 2014 we will find out how many Health and Social Care organisations and those providing services on their behalf have safeguarding policies, safeguarding plans and safeguarding champions in place. We will then set targets to improve this.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Patient and Client Council**
- **Regulation and Quality Improvement Authority**

What are we trying to achieve?

We want to prevent harm taking place and keep people safe. We also want to respond effectively if there is a concern that someone has been or is likely to be harmed.

Why is it important?

People of all ages have the right to be safe from harm and to have their welfare promoted and human rights upheld.

Standard 10

Chronic Obstructive Pulmonary Disease

Health professionals within **Primary Care** should accurately diagnose, assess and treat everyone suspected of having **Chronic Obstructive Pulmonary Disease** (COPD).

How we know it's working

- By March 2017 we will make sure all GP practices have a register of smokers and/or ex-smokers who are over 35 and on **short-acting beta agonists** to help case finding for COPD.
- By March 2016 we will make sure at least 60% of people with COPD (diagnosed from 1 April 2011) have had their diagnosis confirmed by a breathing test. This will be between3 months before and 15 months after going on the COPD register. By March 2017 this will be at least 80%.
- By March 2017 we will make sure at least 75% of people with COPD have a record of **FEV1** in the last 15 months.
- By March 2016 we will make sure at least 70% of people with COPD have, in the last 15 months, had a **review** from a healthcare professional. This will include an assessment using the **MRC breathlessness scale**. By March 2017 this will be at least 90%.
- By March 2017 we will make sure at least 70% of people with COPD and a **MRC breathlessness score** of more than 3 and/or **functional breathlessness** have been referred for **pulmonary rehabilitation**.
- By March 2016 we will make sure at least 70% of people with COPD and a **MRC breathlessness score** of 3 or more at any time in the last 12 months have had the level of oxygen in their blood recorded within the last 15 months. By March 2017 this will be at least 90%.
- By March 2017 we will make sure we refer at least 90% of people with COPD with **Sp02** levels less than 92% when their condition is stable to the local Home Oxygen Service – Assessment and Review (HOS-AR) service.
- By March 2016 we will make sure at least 90% of people with COPD who smoke have had proper smoking advice. By March 2017 this will be at least 95%.
- By March 2016 we will make sure at least 95% of people with COPD have had the flu vaccine in the last 1 September to 31 March period.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want to prevent COPD where possible, but, as a minimum, we want to slow it down or stop it becoming worse.

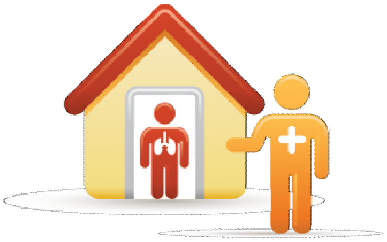
Why is it important?

If we detect COPD early we can stop it becoming worse.

Standard 11

Chronic Obstructive Pulmonary Disease – Specialist Community Team Care

People with **chronic obstructive pulmonary disease** (COPD) who meet the referral criteria should be able to get specialist community **respiratory** team care.



How we know it’s working

- By March 2017 we will find out how many people with severe/very severe COPD are being cared for by a specialist community respiratory team. By March 2018 we will set targets to improve this.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Community specialist respiratory teams**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want all patients with severe COPD to have access to a full range of specialist community **respiratory services**, when needed, seven days a week.

Why is it important?

Patients with severe COPD need effective **chronic** disease management, including timely assessment. This could stop them having to go into hospital.

Standard 12

Chronic Obstructive Pulmonary Disease – self-management

People with **chronic obstructive pulmonary disease** (COPD), and their carers, should be able to learn about the disease and how to manage it themselves. Supported self-management should be part of the care for those who need **pulmonary rehabilitation** and **case management**.

How we know it's working

- By March 2016 we will make sure we give at least 90% of people with COPD individual, face-to-face information and a written self-management action plan. By March 2018 this will be at least 95%.
- By March 2016 we will make sure at least 70% of people with COPD in pulmonary rehabilitation programmes receive individual, face-to-face information and an updated written self-management action plan. By March 2018 this will be at least 90%.
- By March 2016 we will make sure at least 70% of people with COPD who are receiving case management from specialist community respiratory teams have individual, face-to-face information and an updated written self-management action plan. By March 2018 this will be at least 90%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want patients with COPD and their carers to have greater control over their lives and to work in partnership with health professionals. This can happen if patients learn enough about COPD to the point where they can take responsibility for managing it.

Why is it important?

People with COPD and their carers can benefit from having knowledge and an understanding about their condition. If they can work in partnership with the Health Service they can manage their disease better, including how it affects their quality of life. They can also take action quickly if their symptoms get worse.

Standard 13

Chronic Obstructive Pulmonary Disease – management of acute attacks

When their symptoms suddenly become more severe all patients with **chronic obstructive pulmonary disease** (COPD) should have the best standards of management and treatment.

How we know it's working

- By March 2017 we will find out how many GP practices have a system to identify people presenting with a COPD attack at GP practices, out-of-hours providers, emergency departments or **ambulatory care** settings. By 2018 we will set targets to improve this.
- By March 2017 we will find out how many people with a COPD attack presenting in GP practices, out-of-hours providers, emergency departments or ambulatory care settings we have recorded as having a phone or face-to-face follow-up from a GP, practice nurse, community or secondary care within 14 days of the attack. By 2018 we will set targets to improve this.
- By March 2016 we will make sure at least 70% of people with COPD admitted to hospital for more than 24 hours with an attack get care from a respiratory team. By March 2018 this will be at least 90%.
- By March 2016 we will make sure we manage at least 50% of people with COPD in hospital in a respiratory ward or respiratory area. By March 2018 this will be at least 70%.
- By March 2016 we will make sure we note the smoking status, and offer and document advice on stopping, of least 70% of people with COPD admitted to hospital with an attack. By March 2018 this will be at least 90%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want all patients with COPD whose symptoms result in an attack to be able to get an assessment from GPs and community specialist respiratory teams if this will be helpful. If they go into hospital we want respiratory team specialists to see these patients.

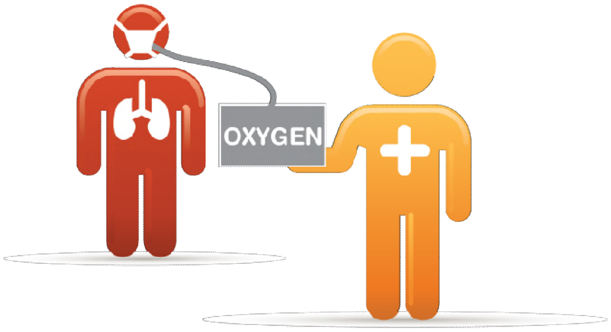
Why is it important?

If the symptoms of people with COPD suddenly become more severe we need to manage them in different ways. The right specialist help will increase their chances of recovery.

Standard 14

Chronic Obstructive Pulmonary Disease – ventilation support

People with **chronic obstructive pulmonary disease** (COPD) admitted to hospital with **respiratory failure** should be assessed for **non-invasive ventilation** in a unit supervised by a respiratory or intensive care doctor.



How we know it's working

- By March 2016 we will make sure at least 90% of people admitted to hospital with respiratory failure have had an **arterial blood gas** assessment on admission to identify respiratory failure. By March 2018 this will be at least 95%.
- By March 2016 we will make sure at least 90% of people admitted to hospital with respiratory failure receive non-invasive ventilation in a respiratory ward or respiratory area. By March 2018 this will be at least 95%.
- By March 2016 we will make sure at least 90% of people admitted to hospital with respiratory failure who receive non-invasive ventilation have a clear management plan. By March 2018 this will be at least 95%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want all people with COPD who have respiratory failure to have an assessment to see if they need non-invasive ventilation. We want 24-hour access to the machine, and the right staff, in all hospitals taking in these patients.

Why is it important?

Non-invasive ventilation improves the chances of survival for patients with COPD who have respiratory failure. It also reduces the hospital stay and can prevent the patient from needing to go into intensive care.

Standard 15

Chronic Obstructive Pulmonary Disease – supported discharge

All people who go into hospital with a **chronic obstructive pulmonary disease** (COPD) attack should have proper discharge planning and follow-up.

How we know it's working

- By March 2016 we will make sure at least 70% of people discharged from hospital following admission for a COPD attack have their discharge completed to include:
    - advice on stopping smoking
    - individual self-management plan
    - inhaler technique checked
    - referral to **pulmonary rehabilitation**
    - referral to a community team for assessment and review for more complex needs.

  By March 2018 this will be at least 90%.
- By March 2016 we will make sure at least 40% of people discharged from hospital after being admitted for a COPD attack have been offered pulmonary rehabilitation within 4 weeks (as long as they fulfil the inclusion criteria). By March 2018 this will be at least 60%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want to make sure that when people take a COPD attack and go into hospital they have good follow-up treatment after they get out.

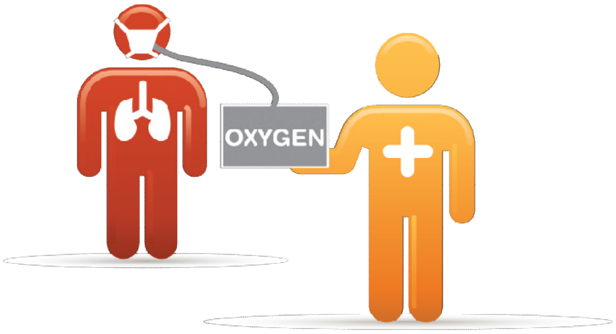
Why is it important?

Good discharge planning and follow-up care stops people from having to go back to hospital. If it is right for the person with COPD, home treatment should be available.

Standard 16

Long-term oxygen therapy

All people needing **long-term oxygen therapy** (LTOT) should be properly assessed before the start of their treatment.



How we know it's working

- By March 2016 we will make sure all HSC Trusts have Home Oxygen Service – Assessment and Review (HOS-AR) assessment processes in place for LTOT and that we have found out how many people who have started the therapy we have assessed. By March 2017 we will set targets to improve this.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want to ensure that we properly check everyone who might have COPD or another respiratory condition before beginning long-term treatment.

Why is it important?

LTOT improves survival rates and reduces hospital admissions for people who have a respiratory condition. It is important to have a thorough assessment to make sure the treatment is appropriate.

Standard 17

Portable oxygen therapy

Portable oxygen therapy should be prescribed for all people already on **long-term oxygen therapy** (LTOT) who wish to continue with the therapy outside the home, but only after assessment by a specialist.

How we know it's working

- By March 2016 we will make sure all HSC Trusts have Home Oxygen Service – Assessment and Review (HOS-AR) assessment processes in place. We will have found out how many people we have prescribed portable oxygen besides LTOT via an oxygen concentrator and following specialist assessment. By March 2017 we will set targets to improve this.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want all patients on LTOT to have portable oxygen outside the home if it is right for them.

Why is it important?

Providing portable oxygen for people on LTOT enables them to leave their home for short periods. This has positive benefits such as increased activity, independence and quality of life.

Standard 18

Specialist oxygen service

Everyone on **long-term oxygen therapy** (LTOT) should have their condition reviewed at least once a year by a specialist oxygen service.

How we know it's working

- By March 2016 we will find out how many people on LTOT had their condition reviewed by the specialist Home Oxygen Service – Assessment and Review (HOS-AR) in the last 12 months. By March 2017 we will set targets to improve this.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want to make sure people continue to receive benefit from their long-term oxygen therapy.

Why is it important?

Where long-term oxygen is prescribed, a review at least once a year will make sure people get the most from their treatment.

Standard 19

Controlled oxygen therapy for COPD

Controlled oxygen therapy should be available to all people with COPD being transported by ambulance.

How we know it’s working

- By March 2016 we will find out how many people with COPD, and who need controlled oxygen therapy, receive it when being transported in an ambulance. By March 2017 we will then set a target to improve this.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want all patients with COPD being transported in an ambulance to have the right controlled oxygen therapy available**.**

Why is it important?

Patients with COPD who have **low oxygen** levels need controlled oxygen therapy when being moved by ambulance. Control is important because too much oxygen can cause respiratory failure in some patients.

Standard 20

Diagnosis of asthma in adults

Everyone suspected of having asthma should have an accurate diagnosis before starting prolonged treatment.

How we know it’s working

- By March 2016 we will make sure at least 80% of people aged 8 or over (diagnosed from 1 April 2006) on the asthma register have their diagnosis re-examined and recorded. This will be between three months before, or, after the diagnosis.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want to ensure that we properly diagnose everyone who might have asthma before beginning long-term treatment.

Why is it important?

Treatment for asthma can last a long time. It is important to have a thorough diagnosis to make sure the treatment is suitable.

Standard 21

Asthma – self-management

All patients with asthma, and their families and carers should have the opportunity to learn about their condition and to find out how to manage it themselves.

How we know it's working

- By March 2016 we will make sure at least 80% of people with **Step-2** asthma and above have a personal consultation and a written self-management action plan.
- By March 2016 we will find out how many people aged over 15 with newly diagnosed asthma Step-2 or above have completed an asthma education programme. By March 2017 we will set targets to improve this.
- By March 2016 we will make sure at least 80% of people aged 14 and above with asthma have attended an asthma education programme and have been asked to show their inhaler technique at asthma review

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want all patients to have the opportunity to understand and self-manage their asthma. This will happen if we offer them the chance to learn about their condition.

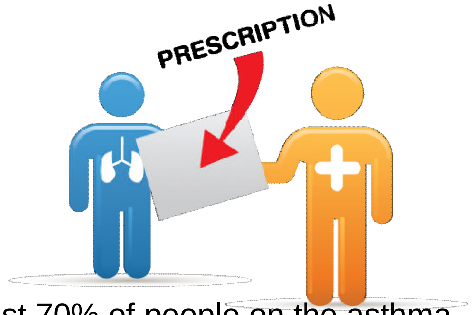
Why is it important?

Evidence shows that patients who use a personalised action plan to self-manage their asthma enjoy better health.

Standard 22

Asthma – ongoing management

All patients with asthma should be on the right medication.



How we know it’s working

- By March 2016 we will make sure at least 70% of people on the asthma register have had a review in the previous 15 months. This will include an assessment of asthma control using **the three RCP questions**.
- By March 2016 we will find out how many people with asthma on **Step-5** treatment we are caring for in secondary care asthma services. By March 2017 we will set targets to improve this.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want all patients diagnosed with asthma to be on medication fitting their condition.

Why is it important?

Usually asthma is treatable with the right medication, and patients can control their symptoms and enjoy a good quality of life.

Standard 23

Asthma – management of asthma attacks

Anyone who takes an asthma attack should have a quick, accurate assessment and get the right treatment.

How we know it’s working

- By March 2016 we will make sure at least 40% of people presenting with an asthma attack to out-of-hours providers have their ability to breathe out tested after being given a **bronchodilator**. By March 2017 this will be at least 50%.
- By March 2016 we will make sure at least 70% of people presenting with an asthma attack to emergency departments have their ability to breathe out tested after being given a bronchodilator. By March 2017 this will be at least 80%.
- By March 2016 we will make sure at least 60% of people presenting with an asthma attack to emergency departments or out-of-hours providers, whose blood is carrying less than 94% of the oxygen it could carry, have their oxygen levels tested after being given a bronchodilator, and the result recorded. By March 2017 this will be at least 80%.
- By March 2017 we will find out how many GP practices have a system to identify people presenting with an asthma attack in GP practices, out-of-hours providers, emergency departments or **ambulatory care** settings. By March 2018 we will set targets to improve this.
- By March 2017 we will find out how many people presenting with an asthma attack in GP practices, out-of-hours providers, emergency departments or ambulatory care settings have been recorded as having a phone or face-to-face follow-up by the GP, practice nurse, community or secondary care within 14 days of the attack. By March 2018 we will set targets to improve this.
- By March 2017 we will make sure at least 70% of GP practices have a register of people at risk of near fatal asthma.
- By March 2016 we will make sure we manage at least 80% of people admitted with acute severe asthma in a respiratory ward or respiratory area. By March 2018 this will be at least 90%
- By March 2016 we will make sure at least 60% of people with acute severe asthma admitted to hospital with an attack get care from a respiratory team. By March 2018 this will be at least 80%.

- By March 2016 we will make sure at least 80% of people admitted with acute severe asthma, who are on a bronchodilator only, are started on inhaled **corticosteroids**. By March 2018 this will be at least 90%.
- By March 2016 we will make sure at least 60% of people admitted with acute severe asthma receive a written discharge care plan. By March 2018 this will be at least 80%.
- By March 2016 we will make sure that at least 90% of people with asthma who smoke have been given appropriate smoking advice, By March 2018 this will be at least 95%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want to quickly assess and manage all patients with the symptoms of an asthma attack.

Why is it important?

Asthma attacks can be life-threatening. Quick and accurate assessment is vital.

Standard 24

Management of difficult asthma

Experienced and skilled specialists should assess, diagnose and manage **‘difficult asthma’** patients.

How we know it’s working

- By March 2017 we will make sure we offer help to all ‘difficult asthma’ patients who could benefit from new therapy types.
- By March 2017 we will find out how many people who attend outpatients with difficult asthma have been managed using national guidelines. By March 2018 we will set targets to improve this.
- By March 2017 we will find out how many people who are admitted to hospital have appropriate planning using national guidelines. By March 2018 we will set targets to improve this.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want all patients with ‘difficult asthma’ to have access to specialist assessment for accurate diagnosis and new drug therapies if they need them.

Why is it important?

When people are on **Step-4** treatment and all people on **Step-5** treatment, that is people with ‘difficult asthma’, their day-to-day lives can be upset. These patients need specialists to accurately diagnose, treat and manage their condition.

Standard 25

Diagnosis of asthma in children and young people

All children and young people who might have asthma should have tests to confirm the diagnosis.

How we know it's working

- By March 2016 we will make sure at least 80% of 8 year-olds and over, with asthma (diagnosed from 1 April 2006), and who have had their diagnosis re-examined and recorded between three months before or after their diagnosis, are on the asthma register.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want to make sure children and young people who might have asthma get a test to make an accurate diagnosis and that there is a clear record of the test result.

Why is it important?

Childhood asthma can be difficult to diagnose. Using tests and trials of different treatments can check if the child is asthmatic or is just suffering from a cough or cold.

Standard 26

Management of asthma in children and young people

All children and young people diagnosed with asthma should get face-to-face information and help to plan for managing their condition themselves.

How we know it’s working

- By March 2016 we will make sure at least 80% of children and young people with asthma have individual face-to-face information and written self-management action planning.
- By March 2016 we will make sure we ask at least 80% of children and young people (under 14) with asthma who attended a review to show how well they can use their inhaler.
- By March 2016 we will find out how many schools have support and training for asthma. We will then set targets to increase this.
- By March 2016 we will make sure that at least 80% of children and young people between age 14 and 20 on the asthma register have been checked within the last 15 months to see if they smoke.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want children and young people with asthma and their carers to get individual management plans for their condition.

Why is it important?

When patients and carers know how to manage and treat their asthma they can take better control and improve their quality of life.

Standard 27

Management of asthma attacks in children and young people

All children and young people who take an asthma attack should get a speedy assessment of how severe the attack is and how it can be managed.

How we know it’s working

- By March 2016 we will make sure at least 60% of children and young people presenting with an asthma attack to emergency departments or out-of-hours providers, whose blood is carrying less than 94% of the oxygen it could, have their oxygen levels tested after being given a **bronchodilator**, and the result recorded. By March 2017 this will be at least 80%.
- By March 2017 we will find out how many GP practices have a system to identify children and young people presenting with an asthma attack within the previous 12 months in GP practices, out-of-hours providers, emergency departments or **ambulatory care** settings. By March 2018 we will set targets to improve this.
- By March 2017 we will find out how many children and young people presenting with an asthma attack at GP practices, out-of-hours providers, emergency departments or ambulatory care settings have been recorded as having a phone or face-to-face follow-up by the GP, practice nurse, community or secondary care within 14 days of the attack. By March 2018 we will set targets to improve this.
- By March 2016 we will find out how many children and young people with acute severe asthma attending emergency departments, ambulatory departments or who are admitted, have been reviewed by phone or face-to-face by an asthma specialist paediatric nurse within 14 days. By March 2017 we will set targets to improve this.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want to check the seriousness of all children’s and young people’s asthma attacks. This is to make sure we are managing their asthma the best way.

Why is it important?

An asthma attack can be life-threatening. It is important that we check children and young people who have had to use the emergency services for an asthma attack. This will help prevent another attack in the future.

Standard 28

Management of serious allergic reactions in children and young people

No child or young person should have a second unmanaged serious allergic reaction.

How we know it's working

- By March 2016 we will make sure all children and young people under 16 who have had emergency treatment for a suspected serious allergic reaction are admitted to hospital under the care of a paediatric medical team.
- By March 2016 we will make sure all children and young people, after emergency treatment for a suspected serious allergic reaction, are referred to a specialist allergy service within two weeks of the allergic reaction (age-appropriate where possible).
- By March 2016 we will find out how many children and young people we routinely prescribe an adrenalin auto-injector and who have not had the diagnosis confirmed at a specialist allergy service. By March 2017 we will set targets to improve this.
- By March 2016 we will find out how many schools attend annual updates on recognising and treating serious allergic reactions. By March 2017 we will set targets to improve this.
- By March 2016 we will make sure at least 50% of specialist staff within the asthma and allergy service have trained in managing the emotional, social and psychological issues of children and young people with serious allergic reaction. By March 2017 this will be at least 90%.
- By March 2017 we will make sure all Trusts develop pathways for the emotional, social and psychological support of children with serious allergic reaction, as set out in Standard 50.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

- **Integrated Care Partnerships**

What are we trying to achieve?

We want specialists to check all children and young people who have had a serious allergic reaction within two weeks.

Why is it important?

Children and young people with a history of serious allergic reaction could die if they suffer another attack. A tendency towards asthma and allergies often go together. It is important for a specialist to study the patient's health history to find out what triggers the reaction and help them to avoid them.

Standard 29

Management of difficult asthma in children and young people

All children and young people with more difficult and severe asthma should have their levels of specialist treatment managed using national guidelines.

How we know it’s working

- By March 2016 we will make sure we give at least 90% of children and young people on specific asthma medicines a steroid alert card.
- By March 2016 we will make sure at least 90% of children and young people with asthma attending outpatients have proper management in line with British Thoracic Society guidelines.
- By March 2016 we will make sure at least 50% of children and young people admitted to hospital with asthma have proper in-patient and discharge planning in line with British Thoracic Society guidelines. By March 2017 this will be at least 60% and by March 2018 at least 80%.
- By March 2016 we will make sure at least 50% of children and young people with **difficult asthma**, who did not respond to treatment and are attending a secondary care service, have a home visit from a specialist respiratory nurse. By March 2017 this will be at least 60% and by March 2018 at least 80%.
- By March 2016 we will make sure at least 50% of children and young people with difficult asthma, who did not respond to treatment and are attending the **tertiary** care service, have a home visit from a specialist respiratory nurse. By March 2017 this will be at least 60% and by March 2018 at least 80%.
- By March 2016 we will make sure at least 50% of specialist staff within the asthma and allergy service have trained in managing the emotional, social and psychological issues of children and young people with difficult asthma. By March 2017 this will be at least 90%.
- By March 2017 we will make sure all Trusts develop pathways for the emotional, social and psychological support for children with difficult asthma, as set out in Standard 50.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want all children and young people with more difficult and severe asthma to have their treatment with specialists and top experts managed using national guidelines.

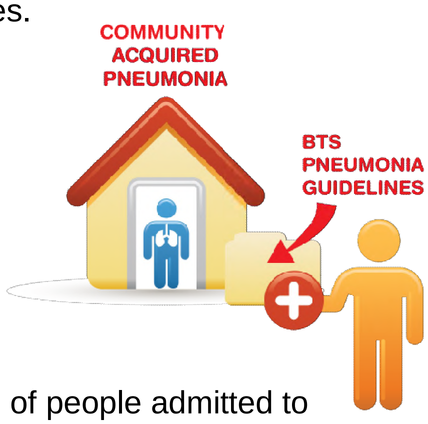
Why is it important?

Children and young people with more difficult and severe asthma need specialist management. This is important for deciding treatment, stopping asthma attacks and reducing the need for medication and hospital admission.

Standard 30

CAP – in adults

All patients with suspected **community acquired pneumonia** (CAP) should have diagnosis and treatment using national guidelines.



How we know it’s working

- By March 2016 we will make sure at least 80% of people admitted to hospital with suspected CAP have a chest x-ray and a review before being started on antibiotics. By March 2018 this will be at least 90%.
- By March 2016 we will make sure at least 80% of people with CAP, whose diagnosis we confirm by chest x-ray, have their first antibiotic dose within 4 hours of arrival at hospital. By March 2018 this will be at least 90%.
- By March 2016 we will make sure at least 80% of people diagnosed with CAP get antibiotics in line with Trust guidance. By March 2018 this will be at least 90%.
- By March 2016 we will make sure there are consultant reviews of at least 90% of people diagnosed with CAP within 24 hours of arrival at hospital. By March 2018 this will be at least 95%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want all patients with suspected CAP diagnosed and treated using national guidelines.

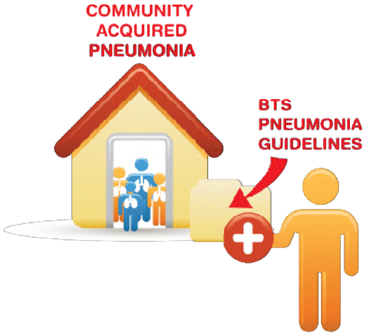
Why is it important?

CAP can be dangerous. If left untreated it can be fatal. Good diagnosis and patient management, using national guidelines, will reduce the number of complications and deaths from this illness.

Standard 31

CAP – in children and young people

All children and young people who might have **community acquired pneumonia** (CAP) should have diagnosis and treatment using national guidelines.



How we know it’s working

- By March 2016, and every six months after this, we will make sure we properly examine and manage at least 75% of children and young adults diagnosed with CAP in line with national guidelines in five key areas. By March 2017 this will be at least 90%.
- By March 2016 we will make sure no more than 20% of children with CAP transferred from another hospital to the Royal Belfast Hospital for Sick Children are admitted to the Paediatric Intensive Care Unit within 24 hours of arrival. By March 2017 this will be no more than 10%.
- By March 2016 we will make sure at least 80% of children and young people with CAP needing to go in to a Paediatric Intensive Care Unit are admitted within six hours of the decision to admit them being made. By March 2017 this will be at least 90%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want all children and young people who might have CAP diagnosed and treated using national guidelines.

Why is it important?

Children and young people with CAP can become very unwell. Good diagnosis and patient management, using national guidelines, will reduce the numbers who have to go in to hospital. It will also reduce the number of complications and deaths from this illness.

Standard 32

OSAHS

All adults who might have **obstructive sleep apnoea/hypopnoea syndrome** (OSAHS) should have specialist attention led by a respiratory doctor.

How we know it’s working

- By March 2017 we will makes sure all Trusts have specialist OSAHS services that can provide an overnight screening test, limited sleep studies and **continuous positive airway pressure** (CPAP) provision.
- By March 2017 we will make sure we assess and examine at least 50% of people with suspected severe OSAHS, or those working in safety critical occupations, within 6 weeks. By March 2018 this will be at least 80%.
- By March 2017 we will make sure we assess and treat at least 50% of people with lower risk OSAHS in line with Health Service waiting time targets. By March 2018 this will be at least 80%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want all adults who might have OSAHS to be referred and assessed by specialists using national guidelines and procedures.

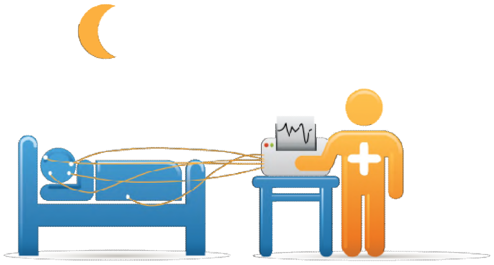
Why is it important?

Adults with OSAHS suffer from poor quality sleep, a poor memory, low concentration and daytime sleepiness. This can lead to accidents at work and in the car, as well as an increased risk of high blood pressure and other diseases related to the heart and blood vessels.

Standard 33

OSAHS - full polysomnography (PSG)

All people who might have **obstructive sleep apnoea/hypopnoea syndrome** (OSAHS) should have timely and proper access to in-patient full **polysomnography** (PSG) in the regional respiratory centre.



How we know it’s working

- By March 2016 we will make sure the regional respiratory centre has set up a regional OSAHS service for people needing full PSG.
- By March 2016 we will make sure at least 60% of people whose sleep study result is normal but who still might have OSAHS, have an overnight in-patient full PSG. By March 2017 this will be at least 80%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want all those who might have OSAHS to be able to have PSG to diagnose their condition.

Why is it important?

Although we can diagnose most cases of OSAHS by a sleep study, we can still miss some sleep disorders. Access to full PSG, the gold standard in investigating OSAHS, is essential.

Standard 34

OSAHS – lifestyle factors

All patients with **obstructive sleep apnoea/hypopnoea syndrome** (OSAHS) should be given information about the lifestyle factors contributing to their condition.

How we know it's working

- By March 2016 we will make sure all Trusts have set up a system to check that all people with OSAHS complete the lifestyle form and get proper advice or referrals.
- By March 2016 we will make sure that Trusts have at least 80% of their medical, nursing and **respiratory physiologists** staff trained in advising on smoking, alcohol, weight management and behaviour changing techniques. By March 2017 this will be at least 90%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want all patients to get information on how to manage their lifestyle to treat their condition.

Why is it important?

Obesity, alcohol, and smoking can be associated with OSAHS. If they are, information on lifestyle change is an important part of treatment.

Standard 35

OSAHS – CPAP treatment

All people with **obstructive sleep apnoea/hypopnoea syndrome** (OSAHS) should be able to get **continuous positive airway pressure** (CPAP) treatment, and regular review and follow-up by respiratory specialists.

How we know it’s working

- By March 2016 we will make sure at least 95% of people who meet the urgent referral criteria have started CPAP within 4 weeks.
- By March 2017 we will make sure we treat at least 80% of people on CPAP in line with the regionally agreed pathway.
- By March 2017 we will make sure at least 40% of people having CPAP are reviewed annually and checked for adherence. By March 2018 this will be at least 60%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

It is important there is proper support and monitoring to ensure that CPAP therapy is working as well as it should.

Why is it important?

CPAP therapy is the best treatment for OSAHS sufferers. It involves wearing a mask at night. Some patients cannot tolerate this, so it is important that we review and follow-up the treatment.

Standard 36

OSAS in children and young people

All children and young people with **obstructive sleep apnoea syndrome** (OSAS) should have an assessment and speedy access to treatment.

How we know it’s working

- By March 2016 we will make sure all Trusts have a nominated clinician who is be able to start and interpret investigations for children and young people with suspected OSAS and make suitable referrals for those with abnormal studies.
- By March 2016 we will make sure at least 95% of children and young people with suspected OSAS failing first line treatments, who are deemed suitable for CPAP, get access to suitable equipment and training in its use within 2 weeks or 9 weeks, depending on urgency.
- By March 2016 we will make sure at least 95% of children and young people with a diagnosis of OSAS have a named link respiratory nurse who can access the **multidisciplinary** team at the Royal Belfast Hospital for Sick Children.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Royal Belfast Hospital for Sick Children**

What are we trying to achieve?

We want all children and young people with OSAS to have an assessment to see how severe their symptoms are, and then to be treated quickly.

Why is it important?

OSAS in children can result in complications such as daytime sleepiness, poor school performance and behaviour disturbances. An assessment can provide an accurate diagnosis and highlight the best treatment. CPAP treatment should be available to the small number who do not respond to having their tonsils and adenoids removed.

Standard 37

Long-term ventilation (LTV) for adults

Adults requiring, or who might need **long-term ventilation** (LTV), should be able to get services that improve survival and quality of life, avoid unplanned admissions to hospital and support their choice for **end of life care**.

How we know it’s working

- By March 2016 we will find out how many people are at risk of **neuromuscular respiratory failure** and who have had an annual assessment of **forced vital capacity** (FVC) or an equivalent assessment and a symptom check for neuromuscular respiratory failure and **Sp02** measurement. By March 2017 we will set targets to improve this.
- By March 2017 we will find out how many people with **motor neurone disease** have a 3-monthly assessment of FVC or an equivalent assessment and symptom check for neuromuscular respiratory failure and Sp02 measurement within the first 36 months of diagnosis (unless already on **non-invasive ventilation**, or progressing very slowly and not requiring frequent monitoring). By March 2018 we will set targets to improve this.
- By March 2017 we will find out how many people with symptoms of neuromuscular respiratory failure or with FVC less than 50% (or **inspiratory pressure** less than 40 cm water) sitting or lying, are assessed and reviewed by a regional specialist multidisciplinary team every 6 months. By March 2018 we will set targets to improve this.
- By March 2017 we will find out how many people with complex needs on community LTV have access to support from a **tertiary** centre specialist respiratory nurse. By March 2018 we will set targets to improve this.
- By March 2016 we will make sure all Trusts have named specialist leads to provide shared care support to people during acute admissions and for those who are unable to travel to regional services.
- By March 2016 we will make sure all Trusts have named specialist leads to provide support across acute and community services for people with COPD and OSAHS and **obesity hypoventilation syndrome**.
- By March 2017 we will find out how many people require cough augmentation equipment and how many access it at time of discharge from hospital or within 4 months of the decision to provide it when being managed in the community. By March 2018 we will set targets to improve this.
- By March 2017 we will make sure at least 50% of people with motor neurone disease, who require cough augmentation equipment, access it within 2 weeks of the decision that they need it being made. By March 2018 this will be at least 70%.

- By March 2017 we will find out how many people with symptoms of neuromuscular respiratory failure have had:
    - communication about their **prognosis**;
    - shared decision-making on ceilings of care;
    - advance care planning; and
    - discussion on their preferred place of care.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want people who need, or might need, a long-term ventilator at home to help them breathe, to have access to one.

Why is it important?

Providing coordinated complex home ventilation services prevents people from dying prematurely and improves the quality of life for people with long-term conditions.

Standard 38

Long-term ventilation (LTV) for children and young people

All children and young people who need, or might need, **long-term ventilation** (LTV) or **nocturnal non-invasive ventilation** (NNIV) support at home to help them breathe should have access to a specialist **multidisciplinary** team.

How we know it's working

- By March 2016 we will make sure at least 80% of children and young people requiring NNIV/LTV get an assessment and regular follow-up by the specialist regional multidisciplinary team.
- By March 2016 we will admit at least 60% of children and young people requiring inpatient sleep studies within 13 weeks. By March 2017 this will be at least 70%, and by March 2018 it will be 100%.
- By March 2016 we will make sure we discharge at least 70% of children and young people requiring LTV, where the decision has been made to discharge to home or step-down care, within 6 months. By March 2017 this will be at least 80%, and by March 2018 it will be at least 90%.
- By March 2016 we will find out how many children and young people starting ventilation support, who at critical periods have specific play therapy to support and improve how they get on with the ventilation support, By March 2017 we will set targets to improve this.
- By March 2016 we will make sure at least 50% of children who require cough augmentation equipment can access it within 4 months of the decision to provide it. By March 2018 this will be 100%.
- By March 2016 we will make sure the initial and essential investigations and treatment of at least 20% of children and young people are within appropriate times. By March 2017 this will be at least 40% and by March 2018 at least 60%.
- By March 2016 we will find out how many children and young people, who require psychological support, received it from a named psychologist with an interest in **respiratory disease** within 15 weeks. By March 2017 we will set targets to improve this.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want children and young people who need, or might need, a long-term ventilator at home to help them breathe, to have access to a specialist multidisciplinary team.

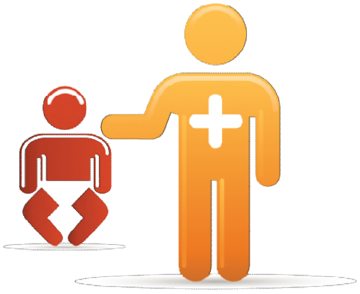
Why is it important?

It is important that children who need ventilators to help them breathe have their condition well managed. The success of this depends on home and hospital working together and good communication with the specialists.

Standard 39

Cystic fibrosis – newborn babies

All babies born in Northern Ireland should be checked for **cystic fibrosis** (CF).



How we know it’s working

- By March 2016 we will find out how many babies born and still living in Northern Ireland have a conclusive blood spot screening result recorded on the Child Health System by 17 days of age. We will check this in March 2017 and March 2018.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want all children born here to be checked for CF.

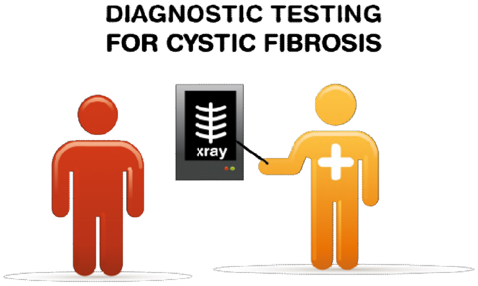
Why is it important?

If we diagnose CF early, babies’ chances of survival improve and the overall state and severity of the illness may become more manageable.

Standard 40

Cystic fibrosis – specialist centre diagnosis

Everyone suspected of having **cystic fibrosis** (CF) should be referred to a specialist centre for diagnosis.



How we know it's working

- By March 2016, March 2017 and March 2018 we will aim for 100%, but will make sure at least 95% of babies suspected of having CF (where 2 mutations of a gene linked to CF have been identified) have their first clinical appointment with the CF team by 28 days of age.
- By March 2016, March 2017 and March 2018 we will aim for 100%, but we will make sure at least 80% of babies suspected of having CF (where less than two mutations of a gene linked to CF has been identified and a blood test finds increased levels of **immunoreactive trypsinogen** (IRT) have their first clinical appointment with the cystic fibrosis team by 35 days of age.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want everyone suspected of having CF to be referred to a specialist centre for diagnosis.

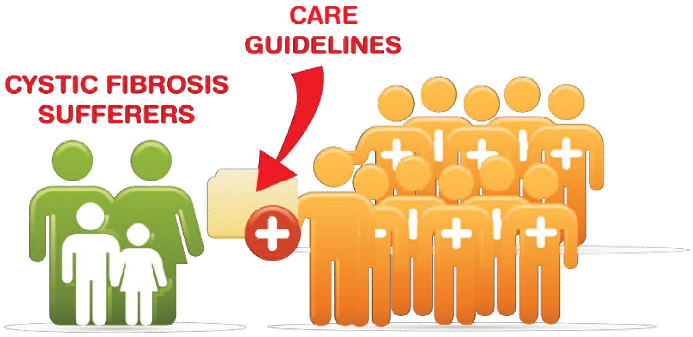
Why is it important?

If we diagnose CF and refer patients to specialist centres early on, their chances of survival improve and the overall state and severity of the illness may become more manageable.

Standard 41

Cystic fibrosis – specialist multidisciplinary team

Everyone with **cystic fibrosis** (CF) should have their care guided by specialist **multidisciplinary** teams.



How we know it’s working

- By March 2017 we will make sure at least 90% of adults with cystic fibrosis have the details about their **FEV1** % predicted, **BMI** and **sputum microbiology** recorded yearly on the CF register.
- By March 2017 we will make sure the details of at least 90% of children up to the age of two have their BMI and their sputum microbiology recorded yearly on the CF register.
- By March 2016 we will make sure the details of at least 90% of children up to the age of 5 who can perform **spirometry** have their FEV1 % recorded yearly.
- By March 2016 we will make sure at least 90% of adults and children are happy with the communication and information they get from the multidisciplinary team.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want all people with CF to have specialist multidisciplinary teams to guide and manage their care.

Why is it important?

Care guided by specialist multidisciplinary teams improves the quality of life and survival chances of people with CF.

Standard 42

Cystic fibrosis – infection control

All patients with **cystic fibrosis** (CF) should be cared for in an environment that keeps reliable control over infections.

How we know it’s working

- By March 2017 we will make sure we test at least 85% of people with CF for infection at least 4 times a year.
- By March 2016 we will treat all people with CF in their own single room.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want all people with CF to get care in an environment with reliable infection control policies.

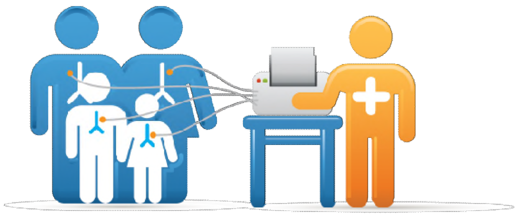
Why is it important?

Infections are damaging to CF sufferers. Effective infection control helps ensure patients’ survival.

Standard 43

Bronchiectasis

All people with suspected **bronchiectasis** should be investigated in line with British Thoracic Society guidelines.



DIAGNOSTIC TESTING FOR BRONCHIECTASIS

How we know it's working

- By March 2016 we will make sure we confirm the bronchiectasis diagnosis of at least 90% of adults by a chest scan.
- By March 2016 we will make find out how many adults with bronchiectasis have been investigated for **allergic bronchopulmonary aspergillosis** (ABPA), **common variable immunodeficiency** (CVID) and for **cystic fibrosis** (CF) in all individuals up to the age of 40. By March 2017 we will set targets to improve this.
- By March 2016 we will make sure we investigate at least 80% of children and young people with suspected bronchiectasis in line with the British Thoracic Society guidelines in **tertiary** care. By March 2018 this will 100%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

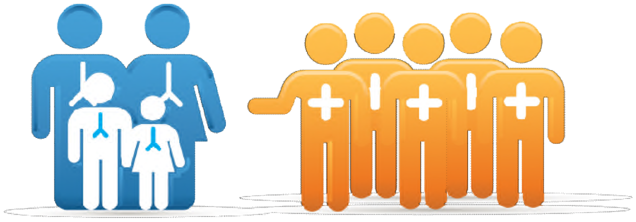
What are we trying to achieve?

Bronchiectasis can lead to other serious conditions such as collapsed lung and heart failure. It is important that children and adults get a proper examination to confirm that they have bronchiectasis.

Standard 44

Bronchiectasis – multidisciplinary respiratory team

All patients with symptoms of bronchiectasis should have treatment by a **multidisciplinary** respiratory team.



How we know it's working

Adults

- By March 2016 we will make sure all Trusts have access to a specialist respiratory team which has at least a respiratory clinician, a specialist respiratory nurse and a physiotherapist with a special interest in bronchiectasis.
- By March 2016 we will make sure a respiratory physiotherapist reviews at least 90% of adults diagnosed with bronchiectasis.
- By March 2016 we will make sure at least 80% of adults with a diagnosis of bronchiectasis had their **sputum bacteriology culture** when their condition is stable sent to be checked and recorded within the last 12 months.
- By March 2016 we will make sure we refer at least 60% of adults with breathlessness affecting their daily living for **pulmonary rehabilitation**. By March 2018 this will be at least 80%.
- By March 2016 we will make sure that at least 80% of adults with bronchiectasis that has got worse have a **sputum** sample sent for testing before treatment.
- By March 2016 we will make sure that at least 80% of adults with bronchiectasis that has got worse have an evaluation of effectiveness.
- By March 2016 we will make sure we offer at least 60% of adults with bronchiectasis that has got worse IV **therapy** at home, if appropriate. By March 2018 this will be at least 80%.

Children and young people

- By March 2016 we will make sure that all children and young people with symptoms of bronchiectasis attend a multidisciplinary service.
- By March 2016 we will make sure that at least 90% of children and young people with bronchiectasis have an annual review, including **spirometry**, **BMI** and **sputum microbiology** where appropriate.

- By March 2016 we will make sure that at least 60% of children and young people with bronchiectasis are tested for infection every three months. By March 2018 this will be at least 90%
- By March 2016 we will make sure that all children and young people with poorly managed symptoms or bronchiectasis that has got worse are admitted to **tertiary** care within 72 hours of the decision to admit them being made.
- By March 2016 we will make sure that all children and young people admitted to tertiary care with bronchiectasis for **IV** antibiotics have their treatment started within 24 hours of admission.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want all patients with symptoms of the lung disease bronchiectasis to have treatment by a multidisciplinary respiratory team.

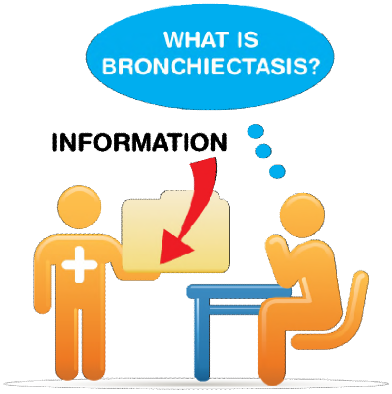
Why is it important?

If multidisciplinary respiratory teams care for patients with bronchiectasis they enjoy better health and spend less time in hospital.

Standard 45

Bronchiectasis – education and self-management

All patients with **bronchiectasis**, and their carers, should have the opportunity to learn about and manage their condition themselves.



How we know it's working

- By March 2017 we will make sure that at least 70% of adults attending secondary care get individual, face-to-face information and a written action plan for managing their condition. By March 2018 this will be at least 80%.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want all patients with bronchiectasis and their carers to have greater control over their condition and to work in partnership with the Health Service.

Why is it important?

Patients with bronchiectasis and their carers can benefit from having knowledge and an understanding about their condition. If they can work in partnership with the Health Service they can respond quickly if their symptoms get worse.

Standard 46

Interstitial lung disease (ILD) diagnosis

Everyone who has or might have **interstitial lung disease** (**ILD**) should have care from a respiratory specialist who has support from other relevant specialists.

How we know it's working

- By March 2017 we will make sure all Trusts have local access to a **radiologist** with expertise in chest imaging.
- By March 2017 we will make sure all Trusts have regional access to a **pathology** service with proper expertise in ILD.
- By March 2016 we will make sure all Trusts have a named lead consultant respiratory doctor with an interest in ILD.
- By March 2017 we will make sure all Trusts have a named specialist respiratory nurse with an interest in ILD.
- By March 2018 we will make sure at least 50% of people with suspected ILD / IPF (**idiopathic pulmonary fibrosis**) have had their case discussed at a local **multidisciplinary** team meeting for ILD.
- By March 2018 we will find out how many people with ILD / IPF we have assessed at a regional centre for the Pirfenidone drug treatment and other new therapies.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**

What are we trying to achieve?

We want a respiratory specialist who has the support of other specialists in different areas to diagnose all ILD patients.

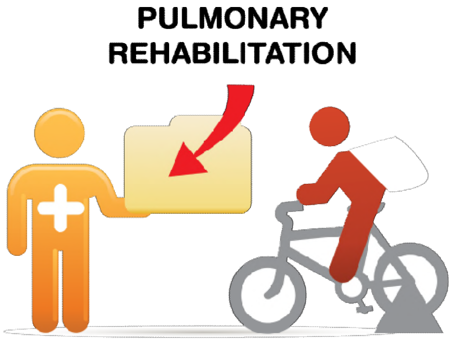
Why is it important?

ILD is a serious illness that can be life threatening. Treatment may need potentially toxic drugs. Experienced respiratory professionals need to diagnose and manage ILD patients.

Standard 47

Respiratory disease – pulmonary rehabilitation

All respiratory patients who need it should have a **pulmonary rehabilitation** programme offered by their doctor or their specialist team.



How we know it's working

- By March 2017 we will make sure we offer pulmonary rehabilitation to at least 50% of people with **chronic obstructive pulmonary disease** (COPD) for whom a referral is appropriate.
- By March 2016 we will make sure people can reach all pulmonary rehabilitation programmes within 30 minutes of travel time.
- By March 2016 we will make sure all pulmonary rehabilitation programmes include all required elements in line with the national guidelines.
- By March 2016 we will make sure all pulmonary rehabilitation programmes can provide ongoing exercise and social support for those who need it.

Who is responsible for making sure it happens?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Integrated Care Partnerships**
- **Primary Care**

What are we trying to achieve?

We want to offer pulmonary rehabilitation programmes in places no more than half an hour's travel time away from all people who need them.

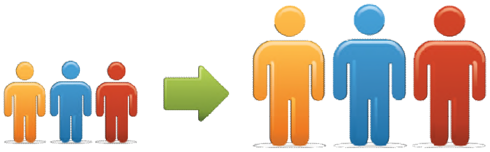
Why is it important?

Pulmonary rehabilitation programmes help people with **respiratory disease** to breathe better. This means they can get out more and do more for themselves, which improves their life.

Standard 48

Chronic respiratory disease – transitional care

All young people with **chronic** respiratory disease should be able to move smoothly into adult treatment services as soon as they leave children's services.



How will we know it's working?

- By March 2017 we will make sure all Trusts can meet the standard set for arrangements to move young people to adult services for chronic respiratory diseases.

Who is responsible for making this happen?

- **Public Health Agency**
- **HSC Board**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want all young people with respiratory diseases to move smoothly into adult treatment services.

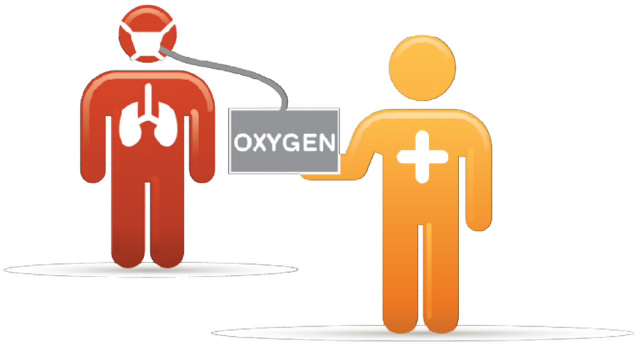
Why is it important?

Moving into adult treatment services can be a time of difficulty for young patients. It is important we make the transfer as smooth and easy as possible to keep continuity of care and support, and control of the disease.

Standard 49

Severe respiratory disease – acute oxygen therapy

All patients with **low oxygen** levels should have oxygen prescribed to get the oxygen in their blood as near to normal as possible.



How will we know it’s working?

- By March 2016 we will make sure we prescribe oxygen therapy using a target saturation range in at least 60% of people admitted to hospital who need oxygen therapy. By March 2017 this will be at least 80%.

Who is responsible for making this happen?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Integrated Care Partnerships**
- **Primary Care**

What are we trying to do?

We want to make sure that all patients with low oxygen get an oxygen prescription for the right amount.

Why is it important?

Both too much oxygen and too little oxygen can be dangerous for severely breathless patients. By having a system for prescribing and monitoring oxygen we can avoid these dangers.

Standard 50

Severe respiratory disease – social and emotional support

All patients, and their families and carers living with severe **respiratory disease** should be offered emotional, social, leisure and exercise opportunities to support their health and wellbeing.

How will we know it’s working?

- By March 2018 we will make sure all local areas (with a population of around 80,000) have patient self-help support groups supported and facilitated by the HSC Trusts.
- By March 2018 we will make sure all local areas (with a population of around 80,000) have general expert patient programmes available for those with respiratory disease.
- By March 2018 we will make sure at least 80% of people on specialist community respiratory team caseloads have a **holistic assessment** and action planning for their social and emotional support needs.
- By March 2018 we will make sure all **local commissioning group** (LCG) areas have timely access to psychology services for those with severe anxiety and depression secondary to respiratory disease when other interventions are not enough.
- By March 2018 we will make sure we have offered at least 80% of people on pulmonary rehabilitation a move on to local exercise and support groups.
- By March 2018 we will offer formal carers assessment, where appropriate, to at least 90% of carers of people with respiratory disease who are on community team caseloads.

Who is responsible for making this happen?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want to support emotional and social needs by setting up self-help and support networks in every locality for respiratory disease sufferers and their families and carers.

Why is it important?

It is important that Health Service staff help patients and carers affected by severe respiratory conditions to develop and keep strong social networks right for their circumstances.

Standard 51

Respiratory disease – information

All respiratory patients and their families and carers should get information about the choices they have for managing their condition and their wider support service options.

How will we know it’s working?

- By March 2017 we will make sure all local areas (with a population of around 150,000) have lists of services available in different written formats.
- By March 2017 we will make sure there is information about respiratory services and support and links to lists of services available on the HSCB and NI Direct websites.
- By March 2016 we will find out how many people with **respiratory disease** are accessing online support groups via the HSC website. By March 2017 we will increase this figure by 10%. By March 2018 we will increase the original figure by 20%.
- By March 2016 we will find out how many carers of people with respiratory disease are accessing online support groups via the HSC website. By March 2017 we will increase the original figure by 10%. By March 2018 we will increase the original figure by 20%.

Who is responsible for making this happen?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want to provide high-quality information to respiratory patients and their families and carers about their condition, its treatment and care. We also want to provide information about patients’ wider community, social and wellbeing support options.

Why is it important?

Well-informed patients and their families and carers can take greater control of managing their illness, reduce its impact and create the best possible quality of life.

Standard 52

Respiratory services – training

All relevant HSC staff should be appropriately trained to meet modern standards and have the necessary knowledge, skills and competencies to provide respiratory services and manage respiratory conditions.

How will we know it’s working?

- By March 2016 we will find out how many GP-employed nurses have completed self-assessment in line with standards set by the right training body. By March 2017 we will set targets to improve this.
- By March 2016 we will find out how many Trust-employed specialist paediatric respiratory nurses have completed self-assessment in line with standards set by the right training body. By March 2017 we will set targets to improve this.
- By March 2016 we will find out how many Trust-employed specialist adult respiratory nurses have completed self-assessment in line with standards set by the right training body. By March 2017 we will set targets to improve this.
- By March 2016 we will find out how many Trust-employed specialist respiratory physiotherapists, carrying out pulmonary rehabilitation, have been trained to the standards agreed by the regional respiratory forum. By March 2017 we will set targets to improve this.
- By March 2016 we will find out how many GP practices have a minimum of 1 registered nurse who has completed a recognised post-graduate respiratory course in **chronic obstructive pulmonary disease** (COPD). By March 2017 we will set targets to improve this.
- By March 2016 we will find out how many GP practices have a minimum of 1 registered nurse who has completed an approved post-graduate respiratory course in asthma. By March 2017 we will set targets to improve this.
- By March 2016 we will find out how many GP practices have a minimum of 1 registered nurse who has completed an approved **spirometry** training course. By March 2017 we will set targets to improve this.
- By March 2016 we will find out how many GP practices have a Primary Care HSC professional who has completed training for **smoking cessation**. By March 2017 we will set targets to improve this.
- By March 2016 we will find out how many Trust HSC professionals who provide a respiratory service have completed training for smoking cessation. By March 2017 we will set targets to improve this.

Who is responsible for making this happen?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want all HSC professionals to be appropriately trained in the skills and competencies required for providing respiratory services and managing respiratory conditions.

Why is it important?

Training for **multidisciplinary** healthcare staff will promote high quality care and ensure healthcare workers are equipped to diagnose respiratory conditions accurately, manage people with these conditions well and provide good support for addressing lifestyle factors.

Standard 53

Respiratory disease – medicines management

All people with **respiratory disease** should be provided with medicines information to help them get the most benefit from medicines and to maintain or increase their quality of life.

How will we know it's working?

- By March 2016, 2017 and 2018, we will make sure we prescribe at least 70% of medicines for respiratory conditions in accordance with the Northern Ireland Formulary.
- By March 2016 we will find out how many people with respiratory conditions are accessing a medicines management support service.By March 2017 we will then set targets to improve this.

Who is responsible for making this happen?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

In partnership with healthcare professionals, we want to make sure the medicines people take for respiratory conditions are managed well, so that the right person receives the right medicine in the right dose at the right time.

Why is it important?

Properly prescribed and managed medication can improve the quality of life for people with respiratory conditions.

Standard 54

Respiratory disease – medicines review

People with **respiratory disease** should have a thorough review of all of their medicines at different stages to make sure that their medicines are right and that they participate in the treatment as prescribed.

How will we know it's working?

- By March 2017 we will find out how many people with respiratory disease in secondary care have had their medicines list checked and verified as accurate on admission to hospital. By March 2018 we will then set targets to improve this.

Who is responsible for making this happen?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want to make sure there are regular reviews on the medicines people are taking for respiratory disease.

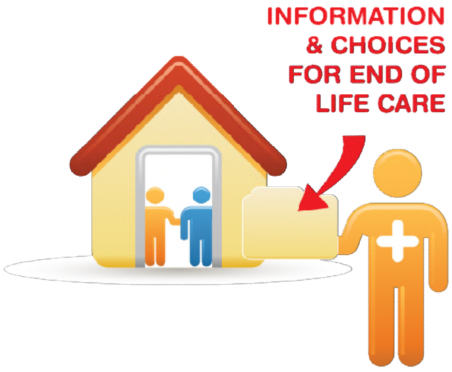
Why is it important?

The right medicine at the right dose at the right time improves people's health outcome, lessens adverse effects and reduces unwanted and unused medicine.

Standard 55

Advanced respiratory disease – palliative and end of life care

People with advanced respiratory illnesses should have their **end of life care** needs identified. Their needs should be coordinated and provided by a key worker at all stages, and they should be supported to die in their preferred place of care, in close collaboration with family and carers.



How will we know it’s working?

- By March 2016 we will make sure we assess the **palliative** care needs of at least 50% of people with respiratory illnesses on community specialist team caseloads. By March 2018 the will be at least 90%.
- By March 2016 we will make sure at least 50% of people with respiratory illnesses, identified as being possibly in their last year of life on community team caseloads, are put on the GP palliative care register and discussed at the practice **multidisciplinary** meeting. By March 2018 this will be at least 90%.
- By March 2016 we will make sure at least 50% of people with a respiratory diagnosis on the Trust palliative care database have had a holistic assessment and a care plan developed (including carer needs). By March 2018 this will be at least 90%.
- By March 2016 we will make sure at least 50% of people with a respiratory diagnosis on the Trust palliative care database have a named key worker. This person will be responsible for ensuring the 24-hour plan of care is communicated to the relevant professionals. By March 2018 this will be at least 90%.
- By March 2016 we will make sure at least 10% of people with respiratory disease on the Trust palliative care database are enabled to die in their preferred place of care. By March 2018 this will be at least 30%.
- By March 2016 we will make sure we train at least 80% of specialist respiratory team members in palliative care skills. By March 2018 this will be at least 90%.
- By March 2016 we will make sure we train at least 95% of specialist respiratory team members in communication skills.

Who is responsible for making this happen?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**
- **Integrated Care Partnerships**

What are we trying to achieve?

We want more informed choice of care that enables people to be more supported to die in their preferred place of care.

Why is it important?

Early identification of palliative and end of life care needs of patients, their family and carers maximises the quality of life for all in terms of physical, emotional, social, financial, and spiritual health and wellbeing.

Standard 56

A GENERIC STANDARD

End of life care

People with terminal illnesses, together with their carers, should be supported to have a good death in the place they prefer.

How will we know it's working?

- By March 2014 we will find out how many people died in their preferred place of care. We will then set a target to improve this.
- By March 2014 we will find out how many people understand what advance care planning is. We will then set a target to improve this.

Who is responsible for making this happen?

- **HSC Board**
- **Public Health Agency**
- **HSC Trusts**
- **Primary Care**

What are we trying to achieve?

We want to improve the **palliative** and **end of life care** and support for patients, families and carers.

Why is it important?

It is important that people have the opportunity and the support they need to make decisions about the way they die. Research shows that quality of life is better and even longer when these needs are met.

Glossary

A

Allergic bronchopulmonary aspergillosis is caused by an allergic reaction to a fungal mould called aspergillus.

Ambulatory care is a type of medical care given to patients who do not need to be admitted to a hospital.

Arterial Blood Gas is a blood test that is performed using blood from an artery. Arteries are blood vessels that carry blood away from the heart.

B

BMI means body mass index. It is a way to calculate a person’s healthy weight range. Health professionals believe a BMI over 25 is unhealthy.

Bronchiectasis is a condition in which some of the airways in the lungs are damaged. This leads to phlegm, which tends to collect in the damaged areas and may lead to recurrent infections.

Bronchodilator – a substance that dilates the airways in the lungs.

C

Case management is the coordination of services on behalf of an individual person who may be considered a case in different settings such as health care, nursing and rehabilitation.

Chronic means the condition is a long-term problem.

Chronic obstructive pulmonary disease (COPD) includes the conditions previously known as chronic bronchitis and emphysemia. COPD occurs when the lungs are damaged, usually by smoking. It can lead to progressively increasing shortness of breath.

Common variable immunodeficiency is a group of conditions in which the immune system cannot make antibodies in response to foreign substances that cause infection.

Community acquired pneumonia (CAP) is pneumonia the patient ‘catches’ outside of hospitals or care facilities.

Community specialist respiratory teams provide care for people with respiratory conditions in their community.

Continuous positive airway pressure (CPAP) is a treatment for moderate and severe OSAHS in which a gentle flow of air is applied through the nose at night. This keeps pressure on the throat above atmospheric pressure, stopping the throat from narrowing and preventing breathing pauses and snoring.

Controlled oxygen therapy is treatment to help patients who have low oxygen levels and who may be harmed by getting too much oxygen.

Corticosteroids are a type of medicine, commonly called ‘steroids’, used to treat a variety of conditions, including inflammation of the airways.

Cystic fibrosis is an inherited disease. There is no cure. It affects babies, children, and young adults. It causes the body to produce thick mucus that clogs the lungs. This leads to life-threatening lung infections.

D

Difficult asthma is asthma at Step-5 on the five-Step scale of asthma symptoms, with 5 being the most serious (see Step- below).

E

End of life care means the care given to a patient who is dying. End of life care helps all those with advanced, progressive, incurable conditions to live as well as possible until they die.

F

FEV1 is the maximum amount of air you can forcefully exhale in one second. It is then converted to a percentage of normal.

Forced vital capacity (FVC) is the amount of air which can be forcibly exhaled from the lungs after taking the deepest breath possible.

Functional breathlessness is shortness of breath without apparent underlying disease

H

Holistic assessment takes into account all aspects of people's lives, the factors that affect them, and what level of independence they have in these areas.

HSC Board (Health and Social Care Board) is the organisation responsible for commissioning, managing and improving health care services in Northern Ireland.

HSC Trusts (Health and Social Care Trusts) provide health and social services across Northern Ireland. There are five trusts. Each one manages its own staff and services and controls its own budget.

Hypopnoea means shallow breathing.

I

Idiopathic pulmonary fibrosis (IPF) is a serious disease where the tiny air sacs of the lungs and the lung tissue next to them become damaged and scarred.

Immunoreactive trypsinogen is a protein produced by the pancreas that is linked to cystic fibrosis.

Independent advocacy describes someone speaking up for another person to help them have a stronger voice and have as much control as possible over their care and their life.

Inspiratory pressure is the level of pressure applied to the lungs when breathing in

Integrated Care Partnerships are formal networks of health and care professionals and those using their services

Interstitial lung disease (ILD) is the progressive scarring of the lungs in which the cause is unknown. There are over 200 forms of ILD, which is characterised by increasing shortness of breath.

IV means intravenous, or injecting medicine or fluid into the veins.

IV therapy, or intravenous therapy, involves the injection of fluids directly into veins.

L

Local commissioning groups (LCG) are responsible for the commissioning of health and social care by addressing the care needs of their local population **.**

Long-term oxygen therapy is the use of oxygen most of the day and night. Patients with COPD should have an assessment of their oxygen levels as they may benefit from this treatment.

Long-term ventilation is treatment that helps patients to breathe who cannot breathe on their own.

Low oxygen means patients are breathless.

M

Motor neurone disease is the name for a rare condition where parts of the nervous system become damaged. This causes progressive weakness, usually with muscle wasting. It occurs when specialist nerve cells in the brain and spinal cord called motor neurones stop working properly.

MRC breathlessness scale is a Medical Research Council scale for grading the degree of a patient's breathlessness.

MRC breathlessness score refers to the levels of breathlessness on a scale defined by the Medical Research Council. The scale is as follows.

Grade	*Degree of breathlessness related to activities*
1	Not troubled by breathlessness except on strenuous exercise
2	Short of breath when hurrying or walking up a slight hill
3	Walks slower than contemporaries on level ground because of breathlessness, or has to stop for breath when walking at own pace
4	Stops for breath after walking about 100m or after a few minutes on level ground
5	Too breathless to leave the house, or breathless when dressing or undressing.

Multidisciplinary means combining different professionals and experts.

N

Neuromuscular respiratory failure is respiratory failure caused by neuromuscular disease. Neuromuscular diseases are diseases of the neuromuscular system (the nerve cells and muscles that work together to move the body).

Non-invasive ventilation is help for a patient’s breathing using a mask or similar device rather than a ventilator machine.

O

Obesity means seriously overweight.

Obesity hypoventilation syndrome is a condition in which severely overweight people fail to breathe rapidly enough or deeply enough, resulting in low blood oxygen levels.

Obstructive sleep apnoea syndrome (OSAS) is a breathing disorder that happens during sleep. Apnoea means a pause in breathing. OSAS happens when a blockage of the upper airways causes the breathing to pause during sleep.

Obstructive sleep apnoea/hypopnoea syndrome (OSAHS) is a breathing disorder that happens during sleep. Apnoea means a pause in breathing. Hypopnoea means shallow breathing. People who suffer from OSAHS breathe shallowly or stop breathing for short periods while sleeping.

P

Palliative means soothing. The purpose of palliative care is to enable people with life limiting illness to live as well as possible until they die.

Patient and Client Council is an organisation that gives an independent voice to patients, clients, carers and communities on health and social care issues.

Pathology is the scientific study of the nature of disease and its causes, processes, development, and consequences.

Polysomnography is a sleep study. This study records certain body functions as you as you sleep, or try to sleep. Polysomnography is used to diagnose sleep disorders.

Primary Care is the name for what is often the first point of contact within the Health and Social Care Services, such as GPs, district nurses, community pharmacists, dentists and opticians.

Prognosis is the likely course of a medical condition.

Public Health Agency is an organisation with responsibility for improving the health and wellbeing of the population of Northern Ireland.

Pulmonary rehabilitation describes a programme of care designed to help chronic respiratory disease patients back to health. It can consist of exercise, education and psychosocial interventions. It can be tailored to an individual’s need. Pulmonary means having to do with the lungs.

R

Radiologist – a medical specialist who uses radioactive substances and X-rays in the treatment of disease.

The three RCP questions are used to during a review of a patient with asthma. They were developed by the Royal College of Physicians. The questions are:

- In the last month/week have you had difficulty sleeping due to your asthma (including cough symptoms)?

- Have you had your usual asthma symptoms (e.g. cough, wheeze, chest tightness, shortness of breath) during the day?
- Has your asthma interfered with your usual daily activities (e.g. school, work, housework)?

One ‘yes’ indicates a medium level of illness, and two or three ‘yes’ answers indicate a high level of illness.

Regulation and Quality Improvement Authority – an independent body responsible for monitoring and inspecting the availability and quality of health and social care services in Northern Ireland, and encouraging improvements in the quality of those services.

Respiratory means relating to breathing.

Respiratory failure happens when the lungs cannot work properly to keep oxygen levels up in the blood.

Respiratory physiologists are specialist who work with patients who have lung, chest wall, airway or blood oxygen problems to understand the causes of their condition and the response to and monitoring of treatment.

Respiratory services means all of the doctors, teams, specialists and facilities the help patients with respiratory diseases.

Review means a check-up.

S

Short-acting beta agonists are a type of drug that relax the airway muscles to give relief in respiratory diseases.

Smoking cessation means stopping smoking.

Sp02 is a measure of the concentration of oxygen in the blood

Spirometry is the most common of the tests that look at how well your lungs work. It shows how well you breathe in and out.

Sputum is mucus that is coughed up from the lower airways.

Sputum bacteriology culture is a test to detect and identify bacteria that infect the lungs or breathing passages.

Sputum microbiology is an investigation into respiratory infection using mucus that is coughed up from the lower airways.

Step-1-5 asthma refers to the steps in the Stepwise approach for treating asthma. The steps go from one to five on three different scales for adults, for children aged 5-12 and for children under five. The ‘step’ of the treatment prescribed by your doctor depends on the symptoms of your asthma.

Syndrome means a group of signs or symptoms that happen together.

T

Tertiary refers to care or treatment provided by an organisation which specialises in a particular area of medicine.

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Date of publication: 05 December 2016