

Clinical Standards ~ *March 2010*

Chronic Obstructive Pulmonary Disease Services

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Contents

1	Introduction to chronic obstructive pulmonary disease	3
2	Development of the clinical standards for chronic obstructive pulmonary disease services	4
3	Clinical standards for chronic obstructive pulmonary disease services	9
	Standard 1: Organisation and delivery of COPD services	10
	Standard 2: Case finding	11
	Standard 3: Diagnosis and periodic review of COPD	12
	Standard 4: Pulmonary rehabilitation	14
	Standard 5: Oxygen therapy	15
	Standard 6: Home support, intermediate care and supported discharge services	17
	Standard 7: Palliative care services	18
4	Appendices	19
	Appendix 1: About NHS Quality Improvement Scotland	20
	Appendix 2: NHS Quality Improvement Scotland standards development methodology	21
	Appendix 3: Membership of the clinical standards for chronic obstructive pulmonary disease services project groups	22
	Appendix 4: Evidence base	25
	Appendix 5: Glossary	28

1 Introduction to chronic obstructive pulmonary disease

Chronic obstructive pulmonary disease (COPD) is a chronic respiratory condition that does not have a known 'cure'. It affects many people, particularly the most vulnerable in our communities, including people from areas with high social deprivation¹. The progression of the disease can be slowed down, but not halted, by stopping smoking. COPD can be characterised by frequent (and sometimes preventable) exacerbations and admissions to hospital. It is the third most common reason for hospital admission in Scotland and has high re-admission rates. Many of the localities with the highest COPD admission rates in the UK are in Scotland². It is a major health issue.

COPD is the only major cause of death in Scotland on the increase. There are thought to be about 100,000 people in Scotland living with COPD, with a predicted increase of 33% in the next 20 years¹. It accounts for over 122,000 bed days and 4,500 deaths every year. Audit Scotland has estimated the direct cost of COPD to NHSScotland to be around £100 million per annum.

Over the last 10 years there has been an increase in research into COPD and its treatment. Treatment options have been developed which place greater emphasis on reducing exacerbations, improving quality of life and activities of daily living. At the same time, it has become clear that this disease causes a huge burden to individuals and their families.

To help address some of these issues, and in keeping with national policy, managed clinical networks (MCNs) and enhanced services for people with COPD are being established in NHS boards.

2 Development of the clinical standards for chronic obstructive pulmonary disease services

In response to previous work on long-term common conditions, NHS Quality Improvement Scotland (NHS QIS) agreed to undertake a programme of work in relation to COPD.

As part of the programme, a project group was convened in January 2009 to develop clinical standards for COPD services. When establishing the project group, NHS QIS ensured, where possible, representation was drawn from across Scotland and included as many disciplines as necessary. A number of subgroups were also convened to consider particular aspects of COPD services. The project group membership is set out in Appendix 3.

Dr John Haughney was recruited as a Clinical Advisor to lead the work of the group. Dr Haughney is a General Practitioner in Lanarkshire and research fellow at the University of Aberdeen. Dr Stan Wright, Consultant in Respiratory and General (Internal) Medicine, was appointed as Chair of the project group.

Quality dimensions

From the outset, the project group was asked to consider the development of standards with reference to the six dimensions of healthcare quality listed in a 2001 Institute of Medicine publication, *Crossing the Quality Chasm*³.

The six dimensions of quality are:

- **Safe:** avoiding injuries to patients from the care that is intended to help them
- **Effective:** providing services based on scientific knowledge to all who could benefit, and refraining from providing services to those not likely to benefit
- **Patient-centred:** providing care that is respectful of, and responsive to, individual patient preferences, needs, and values, and ensuring that patient values guide all clinical decisions
- **Timely:** reducing waits and sometimes harmful delays for both those who receive and those who give care
- **Efficient:** avoiding waste, including waste of equipment, supplies, ideas, and energy
- **Equitable:** providing care that does not vary in quality because of personal characteristics such as gender, ethnicity, geographic location, and socioeconomic status.

Each criterion within the standards was found to apply to at least one of the above quality dimensions.

Scope of the clinical standards for chronic obstructive pulmonary disease services

In October 2008, a scoping exercise was led by Dr Haughney. This exercise had three objectives:

- obtaining opinion from patients, healthcare professionals and others on the key issues to be addressed
- identifying areas of importance from COPD literature, and

- assessing the evidence to support our work.

The process aimed to ensure the final standards were evidence based, relevant and addressed existing quality gaps and service issues both locally and nationally in Scotland.

NHS QIS used the results of these discussions and a review of current literature to produce the Chronic Obstructive Pulmonary Disease (COPD) Standards Development Scoping Report⁴, which identified seven key themes where NHS QIS could support quality improvement. These themes were presented to the project group.

The overall aim of the project group was to develop evidence-based standards that quality assure COPD services in NHSScotland. When developing the standards, the project group made the decision to focus on the 'big things that make a big difference', as these would help improve the service the most. The project group decided to include the following topics:

- organisation and delivery of COPD services
- case finding
- diagnosis and periodic review of COPD
- pulmonary rehabilitation
- oxygen therapy
- home support, intermediate care and supported discharge services, and
- palliative care services.

Additional involvement

The involvement of a range of stakeholders including allied health professionals (AHPs), voluntary sector organisations, patients, carers and the public was of fundamental importance from the outset.

Throughout the progression of the standards, the project group consulted with a range of professionals to ensure the standards incorporated all the issues of key importance to people with COPD. In addition, the project group invited a number of AHPs to attend an event, held in March 2009, which included a series of short discussions with selected members of the project group.

NHS QIS ensured, when setting up the project group, there was patient representation on the COPD standards project group. In addition to this, NHS QIS hosted a public event, led by Dr Wright, in March 2009. People with COPD and carers were invited to give their views on the issues surrounding the COPD standards and to influence their development. NHS QIS used the results of these discussions to produce Clinical Standards for COPD Report, Patient Event⁵, which was presented back to the project group.

Consultation

Following publication of the Draft Clinical Standards for Chronic Obstructive Pulmonary Disease (COPD) Services⁶ in August 2009, a formal consultation was undertaken. During this period, professional groups, health service staff, voluntary organisations and the public were given the opportunity to influence further development of the standards.

In addition, two NHS boards (NHS Borders and NHS Tayside) were peer reviewed against the standards in a pilot exercise in late 2009. The peer review visits allowed the project group to receive feedback on the draft standards and appraise the effectiveness of the review process.

Finalising the standards

NHS QIS received a large and generally encouraging response to the draft standards. All feedback collected throughout the consultation period was considered by the project group and, where appropriate, used to develop the final standards. The response of the project group to each comment is available on the NHS QIS website (www.nhshealthquality.org).

Who do these standards apply to?

The standards apply to all NHS boards in Scotland with responsibility for delivering COPD services, including:

- territorial NHS boards
- National Waiting Times Centre Board
- Scottish Ambulance Service, and
- State Hospitals Board for Scotland.

They apply to any care setting within an NHS board where COPD services are provided including primary, secondary and tertiary care, and to all patients using the services regardless of a person's background or personal circumstances.

The following special health boards will not be directly assessed against the standards, but the development of the standards may have implications for them:

- NHS 24
- NHS Education for Scotland
- NHS Health Scotland, and
- NHS National Services Scotland (in particular Health Facilities Scotland and Information Services Division).

Clinical professions

The standards apply to all clinical professions involved in the care of people with COPD, within the NHS boards specified above. However, specific standards have different implications for different professionals:

Clinical professions		Standard(s) that apply
Allied health professions:	dietitians	1, 4, 6, 7
	occupational therapists	1, 4, 6, 7
	physiotherapists	1, 3, 4, 6, 7
	radiographers	1, 3, 7
	speech & language therapists	1, 3, 7
Ambulance staff:		1, 5, 7
Clinical physiologists (spirometry):		1, 3
GPs:		1, 2, 3, 4, 5, 6, 7
Nurses:	accident and emergency	1, 5, 7
	district / community	1, 3, 5, 6, 7
	geriatric medicine	1, 5, 6, 7
	palliative care	1, 4, 5, 7
	practice nurses	1, 2, 3, 4, 5, 6, 7
	respiratory nurse specialists	1, 2, 3, 4, 5, 6, 7
Out of hours:		1, 2, 3, 5, 6, 7
Pharmacists:		1, 3, 4, 5, 6, 7
Physicians:	accident and emergency	1, 5
	acute care	1, 5
	geriatric medicine	1
	intensive care	1, 5, 7
	palliative care	1, 4, 5, 7
	respiratory medicine	1, 2, 3, 4, 5, 6, 7
	radiology	1, 3
Practitioner psychologists:		1, 3, 4, 6, 7

3 Clinical standards for chronic obstructive pulmonary disease services

Standard 1 Organisation and delivery of COPD services

Standard 2 Case finding

Standard 3 Diagnosis and periodic review of COPD

Standard 4 Pulmonary rehabilitation

Standard 5 Oxygen therapy

Standard 6 Home support, intermediate care and supported discharge services

Standard 7 Palliative care services

Standard 1: Organisation and delivery of COPD services

Standard statement 1a

There is an effective, co-ordinated COPD service provided by the NHS board.

Rationale

COPD is a major health issue in Scotland which impacts on the individuals with the disease, their family, and NHSScotland.

To help address the health issues, and in line with national policy, enhanced COPD services and respiratory MCNs are being established in local NHS boards.

References: 1, 2, 7

Essential criteria

- 1a.1 There is an MCN (or equivalent) within the NHS board which plans, co-ordinates, quality assures and evaluates COPD services.
- 1a.2 The configuration of COPD services within the NHS board reflects the needs of the local population.
- 1a.3 People with COPD are assessed by relevant members of the multidisciplinary COPD service when clinically indicated.
- 1a.4 The MCN (or equivalent) has a COPD action plan for education and training.
- 1a.5 Accurate information on healthcare and non-statutory services, including points of contact, are available to healthcare professionals, people with COPD, their carers and the public.
- 1a.6 People with COPD, and their carers, receive consistent and specific information regarding management of their COPD.
- 1a.7 Relevant patient-specific clinical information is available to all members of the multidisciplinary team at point of contact.
- 1a.8 Personal clinical information is available to people with COPD and, with agreement, their carers.
- 1a.9 COPD services are monitored and evaluated.
- 1a.10 The MCN (or equivalent) collects and acts upon feedback from clinicians, people with COPD and their carers.

Standard 2: Case finding

Standard Statement 2a

People with COPD are diagnosed in the early stages of the disease.

Rationale

There are an estimated 3.7 million people with COPD in the UK. However, only 900,000 people have been diagnosed with the disease. There are approximately 100,000 people in Scotland diagnosed with COPD.

Early diagnosis of COPD could lead to earlier intervention which might help improve symptoms, increase activities of daily living and quality of life, reduce exacerbations and even, through smoking cessation, limit disease progression.

Studies have reported pick-up rates of COPD in smokers of between 10–20%. These have been reported to be achieved at modest cost and use of clinician time.

References: 1, 8, 9, 10, 11

Essential criteria

- 2a.1** There is a strategy and implementation plan to identify people with undiagnosed COPD.
- 2a.2** The effectiveness of the case finding programme is monitored and evaluated.

Standard 3: Diagnosis and periodic review of COPD

Standard Statement 3a

People suspected of having COPD have an accurate diagnosis.

Rationale

The accurate diagnosis of COPD relies on clinical judgement based on a combination of history taking, physical examination and the confirmation of the presence of chronic airways obstruction using spirometry.

Spirometry is the accepted method of measuring the airways obstruction in people with COPD and should be performed by staff who have undergone appropriate training and who keep their skills up to date.

Reference: 8

Essential criteria

- 3a.1** The clinical assessment and investigation of people suspected of having COPD includes:
- smoking status/history
 - occupational history (in particular history of contact with noxious fumes and dusts, and/or working in a polluted environment)
 - Medical Research Council (MRC) dyspnoea scale
 - body mass index (BMI)
 - spirometry, and
 - chest X-ray.
- 3a.2** The diagnosis of COPD is confirmed by spirometry.
- 3a.3** The FEV1 is recorded as a percentage of the normal predicted value.
- 3a.4** Staff carrying out spirometry testing are trained and their competency assessed.
- 3a.5** The competence of staff carrying out spirometry testing is maintained.
- 3a.6** Staff interpreting spirometry test results are trained and their competency assessed.
- 3a.7** The competence of staff interpreting spirometry test results is maintained.
- 3a.8** All spirometers are verified and/or calibrated in line with the manufacturer's recommendations.
- 3a.9** Spirometers used for the diagnosis of COPD have a visual display of volume/time and/or the flow/volume loop.

Standard statement 3b

People with COPD are offered a periodic review.

Rationale

COPD is a chronic condition and it is reasonable to have a periodic review to assess whether the condition has changed and to intervene if appropriate.

Anecdotal reports suggest widespread variation in the content and delivery of a periodic review of people with COPD.

Standardised review in primary care is promoted through the General Medical Services Contract Quality and Outcomes Framework (QOF).

Reference: 12

Essential criteria

- 3b.1** People with COPD are offered a periodic review in accordance with the timescales specified in current national guidance.
- 3b.2** The periodic review of people with COPD includes:
- smoking status
 - immunisation status
 - assessment of MRC dyspnoea scale
 - medication review
 - inhaler technique
 - education
 - BMI
 - self-management
 - identification of co-morbidities
 - identification of psychological and social co-morbidity, and
 - an opportunity for anticipatory care planning.

Standard 4: Pulmonary rehabilitation

Standard Statement 4a

Pulmonary rehabilitation is available within the NHS board to people with COPD.

Rationale

Pulmonary rehabilitation has been shown to be an effective treatment for people with COPD.

When delivered by a multidisciplinary team, pulmonary rehabilitation can improve the health-related quality of life, exercise capacity and breathlessness of people with COPD. There is good evidence to support the benefits of pulmonary rehabilitation post-exacerbation.

References: 8, 13, 14

Essential criteria

- 4a.1 Pulmonary rehabilitation is offered to people with COPD with an MRC dyspnoea scale of 3 or more.
- 4a.2 Pulmonary rehabilitation is made accessible to people with COPD with an MRC dyspnoea scale of 3 or more.
- 4a.3 Pulmonary rehabilitation is offered to people with COPD post-exacerbation.
- 4a.4 Pulmonary rehabilitation incorporates:
 - upper and lower body physical training, and
 - disease education (including smoking cessation) and medication use.

Desirable criterion

- 4a.5 Pulmonary rehabilitation incorporates:
 - medication management
 - nutritional advice
 - psychological and behavioural interventions, and
 - occupational therapy.

Standard 5: Oxygen therapy

Standard Statement 5a

There is an effective and co-ordinated domiciliary oxygen therapy service provided by the NHS board.

Rationale

Long-term oxygen therapy improves survival in people with COPD who have severe hypoxaemia. It reduces the progression of pulmonary hypertension.

The supply of oxygen should be prescribed, dispensed and used according to national guidelines and standards.

References: 15, 16, 17, 18

Essential criteria

- 5a.1** People with COPD with an FEV1 of less than 50% predicted have an oxygen saturation measurement taken periodically and when clinically stable.
- 5a.2** People with COPD with an oxygen saturation of less than 92% on air in a stable state are referred for further respiratory assessment.
- 5a.3** People with COPD are prescribed domiciliary oxygen only after formal assessment.
- 5a.4** People with COPD who receive domiciliary oxygen receive a respiratory assessment at least annually.
- 5a.5** People with COPD who receive domiciliary oxygen therapy have access to a wide range of oxygen delivery products based on their clinical needs.
- 5a.6** Oxygen is provided in accordance with environmental national safety guidelines.

Standard Statement 5b

People with an exacerbation of COPD have access to oxygen therapy and supportive ventilation where clinically indicated.

Rationale

The goal of administering oxygen therapy to those with acute illness is to achieve a target saturation. A more detailed assessment with blood gas analysis is required for people with COPD (at risk of hypercapnia). Supportive ventilation is administered according to clinical need and techniques include non-invasive ventilation.

Reference: 19

Essential criteria

- 5b.1** Emergency care contact points have access to pulse oximetry.
- 5b.2** Oxygen is administered in accordance with the British Thoracic Society (BTS) Guideline for Emergency Oxygen Use in Adult Patients.
- 5b.3** Non-invasive ventilation is administered when clinically indicated.
- 5b.4** People with COPD with hypercapnic respiratory failure are provided with an oxygen alert card.

Standard 6: Home support, intermediate care and supported discharge services

Standard Statement 6a

People with COPD have access to home support services (including 'hospital at home', intermediate care and supported discharge) if clinically indicated.

Rationale

In clinical studies, there are no significant differences between inpatient and domiciliary care for acute exacerbations of COPD in selected patients, in terms of mortality, re-admission rates, symptom scores or quality of life measures.

Alternatives to admission and early supported discharge are popular options for some patients with acute exacerbations.

References: 20, 21, 22, 23, 24

Essential criteria

- 6a.1** Home support services are available to people with acute exacerbations of COPD.
- 6a.2** The additional equipment required to provide 'hospital at home' and supported discharge services is available.
- 6a.3** The effectiveness of home support services is monitored and evaluated.

Standard 7: Palliative care services

Standard Statement 7a

People with COPD are managed with anticipatory and palliative approaches, and have access to specialist palliative care if clinically indicated.

Rationale

Palliative and anticipatory care are integral aspects of the care delivered to those living with, and dying from, any advanced, progressive or incurable condition. COPD is such a condition, with specific issues in respect of symptom control. It is important that each patient has their symptoms, problems and concerns (physical, psychological, social, practical and spiritual) assessed, recorded, discussed and acted upon, according to an agreed process, which includes the use of anticipatory care planning tools.

References: 25, 26

Essential criteria

- 7a.1 People with COPD have access to clinicians trained in general palliative care.
- 7a.2 Specialist palliative care is available to patients with complex palliative care needs.
- 7a.3 People with COPD are given the opportunity to discuss anticipatory care planning when clinically appropriate.
- 7a.4 People with COPD are included in the general practice palliative care register when clinically indicated.
- 7a.5 Anticipatory care plans and palliative care summaries are shared with unscheduled care services.

4 Appendices

Appendix 1 About NHS Quality Improvement Scotland

Appendix 2 NHS Quality Improvement Scotland standards development methodology

Appendix 3 Membership of the clinical standards for chronic obstructive pulmonary disease services project groups

Appendix 4 Evidence base

Appendix 5 Glossary

Appendix 1: About NHS Quality Improvement Scotland

NHS Quality Improvement Scotland (NHS QIS) is a Special Health Board that provides support to NHSScotland.

NHS QIS supports NHS boards to improve the quality of patient care by:

- providing advice and guidance on effective clinical practice, including setting standards
- driving and supporting implementation of improvements in quality, and
- assessing the performance of the NHS, reporting and publishing our findings.

NHS QIS has central responsibility to support NHS boards to deliver patient safety and clinical governance across NHSScotland.



The Scottish Health Council, the Scottish Intercollegiate Guidelines Network (SIGN) and the Healthcare Environment Inspectorate are key components of the organisation.

NHS QIS also takes a leading role in co-ordinating the work of the Scottish Patient Safety Programme and provides support to the Scottish Medicines Consortium.

Further information about NHS QIS is available on our website (www.nhshealthquality.org).

Further information on the organisations mentioned above is available on their website.

Scottish Health Council: www.scottishhealthcouncil.org

Scottish Intercollegiate Guidelines Network: www.sign.ac.uk

Scottish Medicines Consortium: www.scottishmedicines.org.uk

Scottish Patient Safety Programme: www.patientsafetyalliance.scot.nhs.uk

Appendix 2: NHS Quality Improvement Scotland standards development methodology

Basic principles

A major part of the remit of NHS QIS is to develop and run a national system of quality assurance of clinical services. Working in partnership with healthcare professionals and members of the public, NHS QIS sets standards for clinical services, assesses performance throughout NHSScotland against these standards, and publishes the findings. The standards are based on the patient's journey as he or she moves through different parts of the health service.

In fulfilling its responsibility to develop and run a system of quality assurance, NHS QIS takes account of the principles set out in *Fair for All* and *Partnership for Care*, to ensure that 'our health services recognise and respond sensitively to the individual needs, background and circumstances of people's lives'. Therefore NHS QIS endeavours to ensure that consideration of equality and diversity issues feature prominently in the design, development and delivery of all its functions and policies.

NHS QIS standards are developed in accordance with the commitments of the National Health Service Reform (Scotland) Act (2004) that state that 'individual patients receive the service they need in the way most appropriate to their personal circumstances and all policy and service developments are shown not to disadvantage any of the people they serve'.

Format of NHS QIS standards and definition of terminology

NHS QIS standards are designed to be clear and measurable, based on appropriate evidence, and written to take into account other recognised standards and clinical guidelines. All NHS QIS standards follow the same format.

Each standard has a **title** that summarises the area on which that standard focuses. This is followed by the **standard statement**, which explains the level of performance to be achieved.

The **rationale** section provides the reasons why the standard is considered to be important.

The standard statement is expanded in the section headed **criteria** that states exactly what must be achieved for the standard to be reached. Some criteria are **essential**, in that it is expected that they will be met wherever a service is provided. Other criteria are **desirable** in that they are being met in some parts of the service, and demonstrate levels of quality that other providers of a similar service should strive to achieve. The criteria are numbered for the sole reason of making the document easier to work with, particularly for the assessment process. The numbering of the criteria is not a reflection of priority.

Clinical governance and risk management standards

Every individual using healthcare services should expect these to be safe and effective. There are existing *NHS QIS Standards for Clinical Governance and Risk Management* to ensure NHS boards can provide assurance that clinical governance and risk management arrangements are in place, and that they are supporting the delivery of safe, effective, patient-focused care and services. The clinical governance and risk management standards underpin all care and services delivered by NHSScotland and provide the context within which NHS QIS service and condition-specific standards apply. The clinical governance and risk management standards are available on request from NHS QIS or can be downloaded from the website (www.nhshealthquality.org).

Appendix 3: Membership of the clinical standards for chronic obstructive pulmonary disease services project groups

COPD services project group

Name	Title	NHS board area/ Organisation
Dr Stan Wright (Chair)	Consultant in Respiratory & General (Internal) Medicine	NHS Forth Valley
Mr Michael Bews	Policy Manager Managed Clinical Networks	British Lung Foundation
Dr Kevin Carter	Physician in Respiratory Medicine	NHS Grampian
Dr Roger Carter	Consultant Clinical Scientist	NHS Greater Glasgow and Clyde
Ms Gill Dennes	Practice Nurse	NHS Fife
Dr Jacqueline Faccenda	Lead Clinician in Respiratory Medicine	NHS Borders
Mrs Elaine Fenton	Primary Care Respiratory Nurse Specialist	NHS Tayside
Ms Susan Geddes	Patient Representative	
Dr John Haughney	Respiratory Clinical Advisor	NHS Quality Improvement Scotland
Dr Anne Hendry	Clinical Lead, Long Term Conditions Collaborative	Scottish Government
Ms Pat Mackie	Patient Representative	
Professor William MacNee	Professor of Respiratory and Environmental Medicine	University of Edinburgh
Mrs Ruth McArthur	Practice Nurse	NHS Lanarkshire
Mrs Alpana Mair	Primary Care Pharmacist/Pharmacist Prescriber	NHS Lothian
Ms Phyllis Murphie	Lead Respiratory Nurse Specialist	NHS Dumfries & Galloway
Dr Patricia O'Connor	Consultant in Emergency Medicine	NHS Lanarkshire

Mrs Jo Pentland	Clinical Specialist Respiratory Physiotherapist	NHS Lothian
Dr Iain Small	General Practitioner	NHS Grampian
Mrs Moira Smith	Patient Representative	

Spirometry subgroup

Name	Title	NHS board area/ Organisation
Dr Iain Small (Chair)	General Practitioner	NHS Grampian
Dr Roger Carter	Consultant Clinical Scientist	NHS Greater Glasgow and Clyde
Mrs Anne Casson	Nurse Co-ordinator/Service Manager	NHS Grampian
Ms Gill Dennes	Practice Nurse	NHS Fife
Professor Andrew Greening	Professor of Pulmonary Medicine	NHS Lothian
Dr John Haughney	Respiratory Clinical Advisor	NHS Quality Improvement Scotland
Dr Ninian Hewitt	Lead Clinician, Respiratory MCN	NHS Lothian
Mrs Gaylor Hoskins	Clinical Scientist/ Specialist Respiratory Nurse	Tayside Centre for General Practice
Professor William MacNee	Professor of Respiratory and Environmental Medicine	University of Edinburgh
Mrs Ruth McArthur	Practice Nurse	NHS Lanarkshire
Mrs Alpana Mair	Primary Care Pharmacist	NHS Lothian
Mr Colin Stewart	Patient Representative	

Oxygen therapy subgroup

Name	Title	NHS board area/ Organisation
Ms Phyllis Murphie (Chair)	Lead Respiratory Nurse Specialist	NHS Dumfries & Galloway
Dr Kevin Carter	Physician in Respiratory Medicine	NHS Grampian
Mr Richard Dietrich	Head of Scotland and Northern Ireland	British Lung Foundation
Dr Jacqueline Faccenda	Lead Clinician in Respiratory Medicine	NHS Borders
Dr John Haughney	Respiratory Clinical Advisor	NHS Quality Improvement Scotland
Professor William MacNee	Professor of Respiratory and Environmental Medicine	University of Edinburgh
Mr Willie McGhee	Project Manager	NHS National Services Scotland
Mrs Alpana Mair	Primary Care Pharmacist	NHS Lothian
Mrs Jo Pentland	Clinical Specialist Respiratory Physiotherapist	NHS Lothian
Mrs Moira Smith	Patient Representative	

NHS QIS would like to thank the following for their input and support during the development of the clinical standards for COPD services:

- Dr Jane Edgecombe (Consultant in Palliative Medicine)
- Dr David Raeside (Consultant Chest Physician)

Appendix 4: Evidence base

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Appendix 5: Glossary

acute care	The immediate and early treatment of patients who attend hospital as an emergency. It is usually provided by specialist teams.
airways obstruction	An abnormal slowing of airflow from the lungs when the patient breaths out (exhalation).
allied health professional (AHP)	A health professional (other than a doctor or nurse) such as physiotherapists, occupational therapists and dietitians.
anticipatory care	Care which helps identify and prevent health problems before they develop.
anticipatory care planning	Clinicians and patients working together to plan anticipatory care.
body mass index (BMI)	A tool used to determine how healthy a person's weight is.
case finding	This is a way to identify people with COPD who have not yet been diagnosed.
chronic	Describes a disease or infection lasting for a long time or that constantly recurs.
chronic obstructive pulmonary disease (COPD)	A chronic lung condition, often related to smoking cigarettes. It is caused by damage to the airways in the lungs, causing them to become narrower and making it harder for air to get in and out of the lungs. Patients, therefore, suffer from shortness of breath.
clinical governance	The system which monitors the quality of health care and services.
clinician	Any healthcare member of staff, eg doctor, nurse, AHP, who is involved in diagnosing and/or treating patients.
co-morbidities	Two or more conditions that a patient has at the same time.
domiciliary care	Health care provided in a patient's home.
domiciliary oxygen	Oxygen therapy provided in a patient's home.
early stage COPD	COPD at a mild stage. This is often the first sign of a problem and leads to the first diagnosis.
emergency care contact	A member of the emergency team. This includes ambulance staff, first responders, emergency staff and GPs.
evidence-based medicine	Developments in medicine that are based on the best available research evidence.
exacerbation	When a patient's symptoms become more severe and they need additional treatment.
forced expiratory volume in 1 second (FEV1)	This is the amount of air a patient can blow out within one second. This is the most frequently used measure for assessing whether a patient has COPD.

General Medical Services Contract Quality and Outcomes Framework (QOF)	This scheme encourages GP practices to provide good quality care. It includes national standards for care and GP practices that take part receive financial incentives and rewards.
home support	Additional help for patients to allow them to be at home when otherwise they would need to be in hospital.
'hospital at home'	Where treatment is provided in the patient's home rather than at a hospital. It is always for a limited period.
hypercapnia	Where there is increased carbon dioxide in the blood.
hypercapnic respiratory failure	A serious condition, caused by breathing difficulties, which requires specialist medical care.
hypoxaemia	Where there is decreased oxygen in the blood.
immunisation	A vaccination to protect against certain diseases.
intermediate care	Intermediate care is used to cover 'hospital at home', 'home support' and 'supported discharge'. It helps patients to move from hospital to their home and enables patients to be treated at home. Care is provided by a range of health staff (including GPs, specialist teams, physiotherapists).
long-term oxygen therapy	Oxygen supplied for long-term use to relieve the symptoms of illness, including COPD.
managed clinical networks (MCNs)	Bringing together patients and health staff to plan services locally, based on local needs and priorities, but according to nationally agreed standards.
Medical Research Council (MRC) dyspnoea scale	A guide to assessing breathlessness.
medication review	A review of a patient's medication to make sure that it is effective and suitable.
monitoring	The routine collection of information and data to make sure that services are provided in line with current standards and guidance.
multidisciplinary team	A group of people, including NHS, community care and local authority staff, who work together to provide care for patients.
NHS board	Another name for health board.
non-invasive ventilation (NIV)	A way of providing breathing support for patients without the need to insert a tube into the patient's windpipe.
oxygen alert card	A warning card that lets staff know that the patient may need a specific dose of oxygen.
oxygen saturation measurement	A measurement of the amount of oxygen in the blood. This is carried out by a device, usually attached to the earlobe of fingertip.

palliative care	Treatment to relieve, rather than cure symptoms, caused by illnesses such as COPD. It can be provided at any stage of an illness, but more usually when at an advanced stage. Palliative care can help people live more comfortably. It often involves families and carers.
palliative care summaries	A summary of information about a patient's palliative care that can be shared between healthcare professionals. It includes information concerning the patient's wishes about treatment.
periodic review	A regular review of a patient's condition.
primary care	Healthcare that is offered in the community and not in hospitals or specialist centres. GPs are an example of healthcare professionals who work in primary care.
pulmonary	Relating to the lungs.
pulmonary hypertension	High blood pressure in the lungs. It is associated with severe COPD.
pulmonary rehabilitation	A programme of treatment and support designed for patients with lung conditions, including COPD. It helps patients to cope with their breathlessness and can also improve the patient's fitness and strength. It is usually provided by a range of NHS staff, including physiotherapists and nurses.
pulse oximetry	A way to measure the amount of oxygen in the blood without taking a blood sample. It is carried out by a device, usually attached to the earlobe or fingertip.
secondary care	Hospital-based care which is provided on an inpatient or outpatient basis. Consultants are an example of healthcare professionals who work in primary care.
self-management	The term used when patients are encouraged to manage their own conditions with support from healthcare professionals and other staff. This might include information about medicines, exercise and lifestyle.
smoking cessation	To stop smoking.
spirometry	A test to help diagnose COPD. A spirometer is a device used to measure the amount of air a person can blow out and how quickly they can do it.
specialist palliative care	Palliative care provided by a specialist team. The team has been trained specially to help care and support patients. The team will consider all the patient's care needs, including physical and spiritual care.
supported discharge service	Extra support, provided in a patient's home, to allow them to leave hospital earlier than usual.
supportive ventilation	Help with breathing usually provided by a machine.
tertiary care	Very specialised care usually provided in a teaching hospital.
unscheduled care	Any care or treatment provided outside a clinic or services usual hours (for example after 6pm) or emergency care. This care is unplanned.

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