

National Respiratory (COPD)  
Framework  
2008

Irish Thoracic  
Society

Health Service  
Executive

Irish College of  
General Practitioners

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## **References**

### **List of Technical Reports (available in separate document)**

1. Survey of General Practitioners on Services for people with COPD 2007
2. Survey of Respiratory Diagnostics Laboratory Resources 2007
3. Survey of the Irish Respiratory Nursing Association 2007
4. Survey of Physiotherapy Services for People with COPD 2007
5. Survey of Acute Hospital Resources for People with COPD 2007
6. Survey of Community Services for COPD patients 2008
7. An Analysis of the Utilisation and Expenditure of Medicines Dispensed for the Management of COPD in Ireland (National Centre for Pharmaco Economics)

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## Executive Summary

Chronic Obstructive Pulmonary Disease (COPD) is serious, preventable and costly. It is an umbrella term for a number of chronic lung disorders formerly called chronic bronchitis, emphysema, chronic obstructive airway disease and chronic airway flow limitation.

Each year, there are as many deaths in Ireland due to respiratory disease as there are from heart disease. Ireland has the highest mortality rate in the EU from respiratory disease, with COPD a major contributor to these deaths. While COPD can affect those who have never smoked, smoking is the trigger in the majority of cases. It also disproportionately affects people from lower socio-economic groups.

Currently COPD is not prioritised compared with other major killers such as cardiovascular disease, yet it exerts a large negative impact on people's lives and on the health service. Health forecasts show that the adverse impact of COPD will escalate in the coming years in Ireland unless a national integrated and structured approach to respiratory health that focuses on evidence-based prevention and care is implemented.

This COPD Strategy was produced by a National COPD Group which was convened in Autumn 2007. The multi-disciplinary group had representatives from the Health Service Executive (HSE), Department of Health and Children (DOHC), Irish Thoracic Society (ITS), Irish College of General Practitioners (ICGP), ANAIL (Respiratory Nurse Specialists) and the Irish Society of Chartered Physiotherapists.

The objectives of the group were to:

- Review scientific literature scientific on prevention and management of COPD
- Review the epidemiology of COPD in Ireland
- Outline the COPD services and initiatives available in Ireland
- Consult with relevant stakeholders
- Make recommendations for the management of people with COPD and its services, having regard to current best practice
- Make recommendations on the development and implementation of an integrated approach to improve respiratory health and the care of people with COPD.

The Introduction to the report outlines the nature of COPD, the policy context, the rationale for developing the strategy and methods and research undertaken. International best practice guidelines, risk factors and Irish burden of illness data were identified. Extensive written consultation took place with key groups and organisations. Focus group work was undertaken

with a patient support group. Information was gathered on current COPD services. Research was commissioned on prescribing patterns for COPD in Ireland.

The main report is divided into three sections. Section A, which follows the Introduction, places COPD in the context of Irish demography, burden of disease in Ireland and risk factors i.e. the **scale of the problem**. Section B examines COPD in the context of current services, including the views of those involved as users and providers i.e. **current provision**. Section C outlines best practice guidelines and focuses on the goals of reducing the burden of disease and the structures needed to achieve these i.e. **the way forward**. The results of seven studies, which were undertaken in preparing this strategy, are contained in a separate 'Technical Reports' document.

## **Section A: Scale of the problem**

COPD is an incurable but largely preventable and treatable chronic disease, which mainly affects those aged over 35 years. It is characterised by chronic slowly progressive decline in lung function with only partially reversible airflow obstruction, systemic manifestations and increasing frequency and severity of exacerbations. The chronic progressive nature of the disease causes irreversible damage to the lungs, limiting a person's ability to breathe and to carry out routine daily activities. As a chronic disease, COPD fits many of the current policies both of the Department of Health and Children and the Health Services Executive.

Worldwide the burden of respiratory disease including COPD is growing. Today as many people die from COPD as die from HIV/AIDS.(1) Currently, worldwide COPD is the tenth leading disease burden.(2) By 2020, it will be the third leading cause of death. (2)

The health implications of the demographic changes in Ireland are discussed in Chapter 2. By 2036, the population aged  $\geq 35$  years could increase by a factor of 51%-94%. COPD prevalence increases with age. The prevalence of COPD for those aged 40 years or older maybe as high as 26%. It increases from approximately 10% in those aged 40-49 years to over 50% in those aged over 70 years.(3) In Ireland, females outnumber males in the older age groups. Given our ageing population and smoking prevalence, especially in women, it is evident that the health burden of COPD in Ireland will continue to increase.

Ireland's health burden due to COPD is outlined in Chapter 3. COPD is the most prevalent respiratory disease in adults. Based on international figures at least 440,000 people in Ireland have COPD, of whom over 180,000 have moderate or severe disease, only half of whom may be diagnosed. (3) Cigarettes are the most common risk factor for COPD, for other respiratory diseases especially lung cancer and for other chronic diseases such as cardiovascular

disease. If diagnosed at a late stage, COPD health interventions are less effective and more costly.

Ireland's death rate from respiratory disease is over twice the EU average and is the highest in Western Europe.(4) Respiratory disease (including lung cancer) kills 20% of people in Ireland. COPD is a major contributor to these deaths. For people with COPD, influenza and pneumonia can trigger a disease exacerbation, necessitate a hospital admission and precipitate death. For Irish women, respiratory disease (including lung cancer) is the second highest cause of death (21%) after non-respiratory cancer (23%). Between 1984-2006, the downward trends in deaths in Ireland from coronary heart disease (CHD) averaged 3.5% annually while that for respiratory disease averaged only 1.4%.

COPD is inversely associated with socio-economic status. There is a 200% difference in Irish COPD death rates between the lowest and highest occupational groups. Furthermore 69% of excess winter mortality from respiratory disease in Ireland arises in the poorest three socio-economic groups. Those aged over 65 years are most affected. (5) Smoking is also inversely associated with socio-economic status. Ireland's current smoking rate among social classes 5-6 is 37% compared with the national average of 29%. (6) Social class differences in smoking prevalence are also evident from other research e.g. 78% of homeless men in Dublin smoke.(7)

COPD mortality and morbidity, based on hospital utilisation data, do not provide the full picture of the burden of COPD burden. People with COPD, once diagnosed, are mainly managed in the primary care setting. Surveys have shown that 6.4% of Irish adults (aged over 18 years) report chronic airways disease and 8.0 % of 20-44 year olds have bronchitis.(8, 9) In 2004, 530,277 workdays were lost as short term work absences due to respiratory diseases.

Respiratory diseases, largely represented by COPD, are the third most common cause of acute hospital admission. Over the 10-year period 1997-2006, other than an increase amongst females, there was little change in numbers of COPD in-patient discharges. In 2006, diseases of the respiratory system (including lung cancer) accounted for 5.7% of in-patient hospital discharges and 12.4% of acute hospital bed days.

COPD, together with pneumonia, is the dominant principal respiratory diagnosis for those  $\geq 35$  years of age admitted to acute hospitals. Of those hospitalised with COPD in 2006, 91% had additional co-morbidities, 6.5% required ventilation and 29% were repeat admissions with the same diagnosis. The average cost of COPD per hospital in-patient care was €6,494 i.e. 39% higher than the average case cost (€4,677).

In 2006, respiratory disease cost the Irish health service at least €437million. Drug prescription rates for respiratory disease are among the highest for any body system. These costs did not include long term oxygen therapy (LTOT), supply of nebulisers or vaccines. In addition to cost to the health services there is a wider cost to the patient, family and society – e.g. the 530,277 workdays lost in 2004.

Chapter 4 discusses COPD risk factors. The risk of developing COPD results from host-environment interaction. Cigarette smoking is the major risk factor, featuring in 85% of people with COPD. Smoking prevention and smoking cessation are the most important measures to counteract the COPD epidemic. Most of those affected have smoked over 20 pack years (20 per day for 20 years).(10) In high-income countries such as Ireland, WHO estimates that 73% of COPD mortality is related to smoking.(2) In Ireland, 29% of those aged 18 years and over currently smoke (31% males, 27% females), a figure which is largely unchanged since 2002.(6) Among those aged 18-35 years, the rate is 35%.

The natural history of COPD is variable. The rate of decline of lung function (Forced Expiratory Volume or FEV<sub>1</sub>) after 25 years of age is 15 - 30 mL per year. In 'susceptible' smokers who continue to smoke, the decline of lung function averages 60 mL per year.(11, 12)

The genetic risk factor best documented for COPD is alpha-1 anti-trypsin (AAT) deficiency. It affects 1-3% of those with COPD. Those detected to date in Ireland have been at the more severe end of the COPD scale. Historically COPD has been more frequent in men than in women. Recently COPD is increasing among women as smoking habits increase. There is an overlap of up to 30% between people with a diagnosis of COPD and asthma.(13, 14)

Over their lifetime people are exposed to a variety of inhaled particles.(15) The World Health Organisation (WHO) estimates that urban air pollution causes 1% of COPD cases in high-income countries. In Dublin, in the year following the banning of bituminous coal there were approximately 116 fewer respiratory deaths.(16)

Occupational dust, chemicals and vapours can both cause and increase the risk of COPD. (17) Among adults aged 30-75 years the fraction of COPD attributable to work is estimated at 19.2% overall.(18) Following the 2004 Irish smoke free legislation, bar workers' exposure to second hand smoke went from 30 hours per week to zero. Individuals highly exposed to passive smoking (>40hr/week for >5 years) are 48% more likely to present with COPD than are unexposed individuals.(19, 20)

## **Section B: Current provision**

WHO's recommended approach to chronic disease management supports an integrated strategy which promotes population level health promotion and risk reduction. This should be tailored with targeted chronic disease management programmes that are specific to the needs of people with different risks and at various stages of their disease. Ireland supports the WHO approach as evident by recent DOHC and HSE publications e.g. 'Tackling Chronic Disease - A Policy for the Management of Chronic Disease' and Population Health Strategy. (21)

The aim of the COPD service is to prevent disease and to manage those who have COPD. Management of patients with COPD is complex. It involves integrated self-care, primary care, acute hospital care and rehabilitation. These are concurrent overlapping services, not separate or isolated events. Complex problems posed by COPD itself or COPD in the presence of co-morbidities require a variety of health professional input, underlining the need for an interdisciplinary approach. Currently, for many patients with COPD, care can be fragmented across settings and disciplines.

Section B outlines current services (Chapter 5) and reflects the views of providers and users of services (Chapter 6). The services that are required to meet the needs of those with COPD are based on the four components of care of best practice guidelines (Chapter 7) i.e.

Component 1: Assess and Monitor Disease

Component 2: Reduce Risk Factors

Component 3: Manage Stable COPD

Component 4: Manage Exacerbations

Many COPD services are in place but there are gaps that limit the delivery of best practice. These gaps are described in Chapter 5. By way of illustration an example from each of the components is briefly outlined here:

**Spirometry:** Using relatively inexpensive equipment and staff trained both in its performance and interpretation, spirometry is key to the diagnosis of COPD. It should be available to all Primary Care patients who require it. This is currently not the case. Hence diagnosis is delayed until patients have more severe lung damage and require higher levels of care.

**Smoking:** Smoking is a risk factor for 85% of those with COPD. Smoking cessation is the single most effective intervention in COPD. However access to smoking cessation services is limited and restricted in both community and acute hospital settings. The provision of smoking cessation services currently varies within and between settings, e.g. not all hospitals offer smoking cessation services to patients admitted with COPD. Coherent policies towards smoking cessation services are vital

to both the primary prevention of COPD and the secondary prevention of COPD, as well as for others with different smoking related diseases.

**Chronic Disease Management:** To maintain patients at the appropriate level of care, it is essential that chronic disease management programmes are available. These include disease prevention and risk reduction, patient education and appropriate self-management, and integrated primary and secondary care. Pulmonary rehabilitation is acknowledged by all international guidelines as a key component of the management of COPD, helping patients to optimise their function and better manage their disease. Best practice guidelines recommend that patients are referred to pulmonary rehabilitation programmes (PRP) at the time of diagnosis. Currently the supply of PRP is such that most patients (<0.01%) cannot access PRP. In many areas there are no programmes, others have long waiting lists, others do not accept referrals from Primary Care, while the location of many PRPs pose access problems for those without transport.

**Primary Care:** People with exacerbations of COPD mostly present in the Primary Care setting. At times rapid access to respiratory expertise is required. Currently this is not available to the majority of patients. The only option may be acute hospital admission. Lack of services and supports in the community can result in unnecessary lengths of hospital stay. As evident from Chapter 5, the care and treatment provided to people when they experience an exacerbation varies. Schemes to reduce the number of unnecessary admissions to hospital and facilitate early discharge are scarce and not always well integrated across hospital, community and primary care services. Non-invasive ventilation (NIV) should be accessible in all acute hospitals which accept patients with respiratory failure, as it is the initial treatment of choice for patients with Type 2 respiratory failure who require ventilation.

Section B of this report shows that currently services are patchy and fragmented. Service standards and delivery are frequently inadequate. There is geographic inconsistency in service provision. There are inconsistencies in access to essential services in both community and hospital settings and within these settings. There are opportunities to shift from episodic acute hospital care to integrated care focused on primary care. This is the case not just for COPD but also for the majority of chronic respiratory diseases.

## **Section C: The Way Forward**

The impact of COPD on health and health services can be reduced by the implementation of best practice guidelines. The goal is the effective management of people with COPD, using an integrated approach to prevent disease, slow disease progression, optimise quality and

quantity of life and provide care in the most appropriate setting. International best practice guidelines for the prevention, treatment and management of COPD are readily available. Those described in Chapter 7 are based on WHO's Global Initiative for Chronic Obstructive Lung Disease (GOLD) with components from other English language guidelines where appropriate.(15)

Effective management of people with COPD is based on the four components, previously mentioned in Section B. Pivotal to disease assessment and monitoring (Component 1) is early accurate diagnosis of airflow obstruction by spirometry, history and functional assessment including disease severity and co-morbidities, followed by individualised management to address symptoms and quality of life.

Component 2 deals with reduction of risk factors, the key to which for the majority is smoking cessation, although other factors such as discussed in Chapter 4 are also of importance.

The approach to managing people with stable COPD (Component 3) is guided by a patient-centred approach, which determines an individual's disease severity and then implements a stepwise management plan, with both pharmacological and non-pharmacological elements, including pulmonary rehabilitation.

Component 4 deals with the management of people with COPD exacerbations: their assessment and treatment, factors which influence where they should be managed and circumstances which require hospital admission.

At all stages of this chronic progressive disease, the emphasis is on early accurate diagnosis, appropriate supported self care, quality of life and effective multi-disciplinary interventions - pharmaceutical and non pharmaceutical - focused on the primary care setting and supported by specialist respiratory expertise.

Chapter 8 describes how to achieve the vision of reducing the burden of respiratory disease, including COPD, including the implementation framework required, through a continuum of disease prevention and care interventions matched to level of health care needs. It became clear throughout the work of this National Strategy Group that while the focus was on COPD as the most prevalent respiratory disease, the implementation framework needed for COPD was similar to that of most other chronic respiratory diseases. Rather than repeat the process for other respiratory diseases, it is proposed that this strategy and implementation framework is adopted as the structure for the delivery of services for all respiratory diseases.

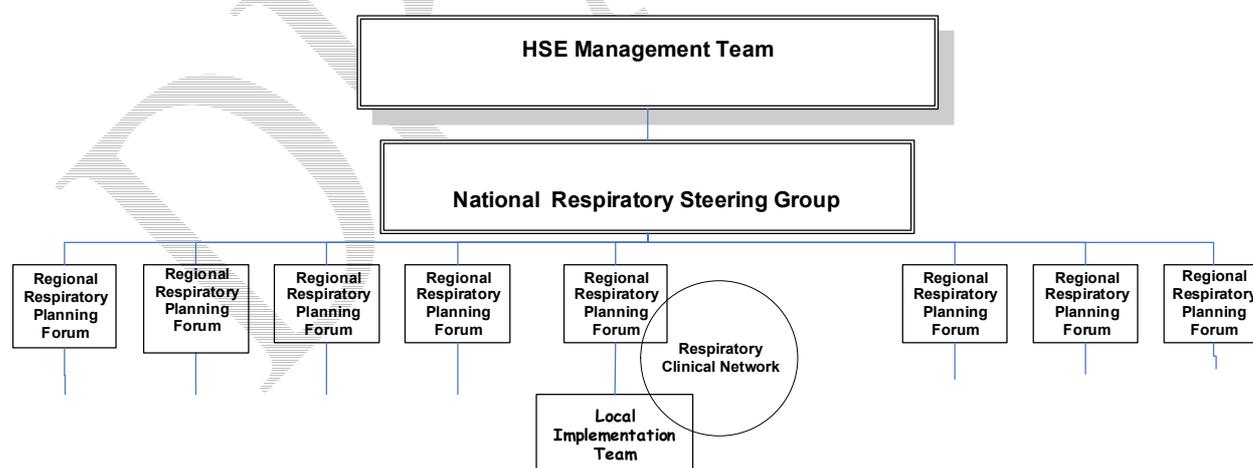
Similarly, the four quality goals to achieve the vision of reducing the burden of respiratory disease, although elaborated on in the context of COPD are, like the structure, valid for other chronic respiratory diseases. These are to:

- Prevent the development and progression of respiratory disease
- Ensure timely access to comprehensive and integrated services in appropriate settings
- Empower patients and carers to actively participate in the management of their condition
- Enable health care workers to deliver an evidence based service.

Each goal has a number of objectives and recommendations, the implementation of which will contribute to reducing the burden of respiratory disease both for patients and the health services. Collaboration and integration will be key factors for success.

Respiratory disease services should be based on a National Plan, implemented at regional level (currently hospital network level), based on regional needs and expertise so as to avoid duplication and gaps. It should be realistic about the workforce and focus on the areas where skills need to be improved, and should be developed in consultation with people with COPD, so as to understand how services are experienced, rather than how they are delivered. How this can be achieved is outlined in the implementation structure below.

**Figure 1 Implementation Framework**



The implementation framework, elaborated on in Chapter 8, has five key levels with specific tasks, suggested membership and a target time frame for its establishment. Briefly these are:

The establishment of a **National Steering Respiratory Group**, under the HSE Management Team, with representatives who have expertise and responsibility for respiratory health, from across the spectrum of health services, to agree a National plan for respiratory service delivery and to provide direction on priorities for national

respiratory service development and delivery, in line with this plan (*Target-September 2008*).

A dedicated **National Office/secretariat** should support the National Steering Group and should act as a centre/repository for respiratory health (including COPD) (*Target-January 2009*).

Regional **Respiratory Planning Fora** (currently at hospital network level) should be established with representatives who have expertise and responsibility for respiratory health. These should come, from across the spectrum of health services and settings in that region and should provide leadership on the development, implementation and evaluation of a Respiratory Plan for that region, based on needs assessment, in line with the plan of the National Steering group (*Target – September 2008*).

The expansion of the current **Local Implementation Teams (LIT)** remit, membership and resources, to implement at that level, the national respiratory plan based on the regional needs assessment (*Target - September 2008*).

(Alternatively, the establishment of separate LITs for chronic disease care starting with respiratory diseases as exemplified by COPD, to implement at that level, the national respiratory plan based on the regional needs assessment (*Target - September 2008*).

**Clinical Networks** for respiratory care, with representatives from relevant health professionals from across care services and settings should be identified, mapped and developed. At a minimum there should be one at each HSE Hospital Network level, pending restructuring, to enable timely access to specialist respiratory support for both professionals and patients regardless of health care setting and ensure that all of the respiratory disciplines in a region/area can work in a co-ordinated manner such that no one person or discipline works in isolation (*Target - January 2009*).

This approach provides an opportunity to make a real and positive impact both on health and health services. It will help achieve the required "shift" in the way care is delivered away from an often reactive episodic approach, frequently delivered in a hospital setting, towards a community based, responsive, adaptable, flexible service.

This together with the quality goals will ensure that by being patient focused not constrained by location that care will support appropriate self management, will be delivered on the basis of need, and at the most appropriate level of care. Shifting, streamlining and integrating how and where services are currently delivered will bring benefits to patients, in terms of reduced

mortality and morbidity, the health services, in terms of reduced healthcare resource utilisation and the wider society.

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# Chapter 1 Introduction

**Chronic obstructive pulmonary disease (COPD) is defined as a preventable and treatable disease which is caused predominantly by cigarette smoking. It is characterised by airway inflammation and airflow limitation that is not fully reversible. It is a progressive disabling disease with significant extra-pulmonary effects and has a major impact on the life of patients, families and carers as well as on the health care system.(15, 22)**

## 1.1 Introduction

Irish people are healthier and are living longer than ever before. Major improvements in health status have taken place e.g. reduced heart disease mortality. However respiratory health status in Ireland remains poor. Ireland's respiratory mortality rate is the highest in the European Union (EU).(4)

The implementation in Ireland of an international evidence-based COPD prevention, diagnosis and management strategy is a national priority. As the population of older people is expected to double in the next 15 years, the burden of illness due to COPD will also escalate.

Worldwide COPD imposes an important societal burden:

- Over 2.5 million people die from COPD each year. This is similar to that of HIV/AIDS.(1)
- COPD is the tenth leading disease burden and by 2020, it will be the third leading cause of death.(2)

COPD does not get the same priority as other major diseases e.g. heart disease or cancer. COPD is under-diagnosed, under-treated and neglected when compared with these other major killers. This may in part be due to the attitude that it is a self inflicted smokers' disease, that it mainly affects elderly people and that it has no effective treatment. However,

- COPD develops in 15% of people who have never smoked
- COPD does increase with age but 5-10% of non-smoking young adults show signs of COPD.(23)

## 1.2 Policy Context

The development of this COPD strategy was guided by national policy documents including the National Primary Care Strategy (21), National Policy on Chronic Illness (24) and Health Services Executive (HSE) plans for transformation and service integration.(25)The

development of a COPD strategy is a priority under HSE Transformation Programme 4: Chronic Illness.

Chronic illnesses are long term conditions that are influenced by many factors including genetic, lifestyle, social, economic, cultural and environmental. They can be treated but not cured. They are now the greatest cause of ill health and health service utilisation in Ireland. (26) Their prevalence will increase as the population ages.

COPD disproportionately affects people from poorer socio-economic groups who are also more likely to die from their illness. (26) Social inequality contributes to a higher proportion of respiratory deaths than any other body system. The difference in respiratory mortality rates between the lowest and highest occupational class is over 200% and COPD is the main reason for this disparity. (27)

A Population Health strategic approach to COPD includes:

- Acting on the wider determinants of health and health inequalities
- Planning for health and social well being
- Using reliable evidence to improve care outcomes
- Making choices for health investment
- Measuring and demonstrating the return for investment in health and social services
- Shifting the balance of care to primary care and health promotion
- Integrating services across the continuum of care
- Working with other sectors to improve health and
- Engaging the population on the issue of their own health.

This report outlines an approach to provide quality integrated health care for people with, or at risk of, COPD. This approach also applies to the majority of respiratory diseases in Ireland.

### **1.3 Understanding COPD**

COPD is an umbrella term for a number of chronic lung disorders, including chronic bronchitis, emphysema, chronic obstructive airway disease and chronic airway flow limitation. COPD is now the preferred term for conditions in patients with irreversible airflow obstruction who previously would have been diagnosed as having chronic bronchitis or emphysema. There is often an overlap in the manifestation of these diseases, for example chronic bronchitis, airway narrowing and emphysema may occur in various combinations. Asthma is associated with reversible airflow obstruction. As there is usually some element of irreversible obstruction with age COPD may be a more correct diagnosis.

COPD has a variable natural history. Impaired lung growth during childhood and adolescence, for whatever reason including recurrent infections or tobacco exposure, may lead to lower maximally attained lung function in early adulthood.(28) This abnormal growth, often combined with a shortened plateau phase in teenage smokers, will increase the risk of COPD. This followed by an accelerated decline in lung function is the single most important feature of COPD (see Chapter 4).

The most common cause of COPD is smoking – a factor in 85% of cases. Other factors, including genetic and occupational exposures, contribute to the burden of COPD.

When the patient's exposure to noxious substances - most often tobacco – continues, progression of COPD is most likely. If exposure is stopped, the disease may still progress, mainly due to the decline in lung function that normally occurs with ageing. Removing the exposure can result in some improvement in function and will slow or even halt the progression of the disease.

COPD is generally a progressive chronic disorder leading to a decline in lung function. While initially its effects can be mild it can eventually become debilitating, costly and potentially fatal. Therefore early diagnosis and effective treatment are essential.

COPD primarily affects people aged over 35 years of age. Significant airflow obstruction may be present before the individual is aware of it as in the early stages people are largely free of symptoms. Even when symptoms develop they may be present for a number of years before individuals seek help. The slow progressive decline in lung function is the result of damage caused by chronic inflammation.

People with severe COPD may become housebound, socially isolated and depressed, becoming increasingly dependant on carers and on the health service. They may suffer exacerbations, which occur with increasing frequency as the disease progresses and in the final stages may develop respiratory failure.

While there is no cure for COPD, smoking cessation can prevent progression and hence significantly improve prognosis. Medication and physiotherapy can help control symptoms while exercise-based rehabilitation programmes can reduce COPD related disability. The combination of these treatments can lead to a general improvement in the quality of life for the patient.

## **1.4 Rationale for Strategy**

The relative burden of respiratory disease in Ireland is rising. One in five Irish people die from respiratory disease. COPD is a major contributor to respiratory ill health and mortality. While COPD related ill-health impacts on the health service, it also has a social dimension in terms of employment absenteeism, disability and poor quality of life for the person with COPD, their family and carers. International studies indicate that the prevalence of mild to severe COPD ranges from 11-26%.(29) The prevalence of moderate to severe disease is 10.7% (excludes GOLD stage I).(3)

Respiratory disease is the most common reason to attend a GP. People with COPD as a principal diagnosis used 111,217 hospital bed days in 2006 when there were 10,712 acute hospital admissions, of which 94% were emergency admissions. Respiratory disease cost the Irish health service at least €437 million in 2006. Drug prescriptions for respiratory disease are among the highest for any body system.

Ireland's prevalence of COPD, the high mortality from respiratory disease together with the changing population size and structure requires a planned, multidisciplinary, integrated strategy to address the respiratory health needs of the population. The implementation of evidenced based interventions and guidelines will lead to health gain in terms of prevention, early diagnosis, effective management and rehabilitation. These will also lead to greater integration of care with an improved focus on prevention and primary health care.

### **1.5 Strategy Development:**

The aim of the group was to develop a strategy for the management of people with COPD in a timely manner in the most appropriate setting. The objectives were to:

- Review current literature pertaining to the management of COPD
- Review the epidemiology of COPD in Ireland
- Outline the range of COPD services and initiatives in Ireland
- Consult with relevant stakeholders
- Make recommendations on the development and implementation of an integrated approach to improve respiratory health and the care of people with COPD.

In Autumn 2007, a National Strategy Group was established with representatives from the HSE, Irish College of General Practitioners (ICGP), Irish Thoracic Society (ITS), Irish Society of Chartered Physiotherapists, ANAIL (Irish Society of Respiratory Nurse Specialists) and the Department of Health and Children (DoHC). This multidisciplinary membership included a range of health professionals (clinicians, allied health professionals, clinical nurse specialists) and senior health management (Appendix 1).

International COPD guidelines were identified by a combination of electronic searches, hand searches and personal contacts. The Group reviewed these guidelines. The GOLD Guidelines were considered to be the most appropriate as the base guideline for use in Ireland, supplemented with components from the other English language guidelines as required.

International literature was used to describe the epidemiology and risk factors for COPD. Data on burden of illness from respiratory disease was extracted from the second edition of INHALE.(30) While that report reflected 2004 data, further analysis was undertaken using 2006 data for COPD morbidity, mortality and costs.

Information was gathered on services and initiatives in place. As part of both the surveys and the consultation (see below), information on initiatives was gathered and added to data available on chronic illness programmes. As this was a national brief, a decision was made to focus on identifying broad service gaps. National surveys were undertaken of:

- GPs in relation to access to services
- Respiratory Nurse Specialists, Physiotherapists and Respiratory Scientists in terms of service provision
- Acute Hospital Managers with regard to services for those with COPD
- Local Health Offices in relation to oxygen and nebuliser policies and supplies and availability of community beds
- Medication prescribing trends (commissioned from the National Centres for Pharmaco-economics (NCPE)).

Consultation was undertaken with a wide a group of stakeholders including:

- Written consultation with over 200 people / groups including patient groups, health care professionals, academic institutions and health service managers. The purpose of the consultation was to explain the strategy objectives and obtain views on services for people with COPD with particular emphasis on initiatives, barriers and suggestions of improvements.
- Links with working groups on HSE transformation and integration.
- Focus group work with a COPD patient support group using themes identified from the literature and those suggested in the written consultation exercise.

Strategy group meetings were focused on recommendations for the development and implementation of an integrated approach to improve respiratory health and the care of people with COPD, having regard both to the evidence and the information available on current service provision.

## **1.6 Conclusion**

Respiratory diseases and in particular COPD are serious, preventable and costly. COPD exerts a large negative impact on people's lives and on the health service. It disproportionately affects those from lower socio-economic groups. International evidence indicates that integrated accessible care can benefit patients with respiratory disease in general, and COPD in particular, and that there is considerable scope to ease the current disease burden. Marked health improvements are possible by focusing on prevention, early diagnosis and clinical management.

This Report presents evidence based interventions that can be used to implement integrated multi-disciplinary prevention, treatment and management programmes in a planned manner. The recommended guidelines adapt internationally accepted guidelines for the Irish population. The Report also outlines an approach for delivery both of these guidelines and of respiratory health services on a national basis which encourages multi-disciplinary intersectoral working. The implementation of this strategy should provide the impetus needed to improve respiratory health in Ireland and to ensure that care is delivered in the most appropriate setting.

## Chapter 2 Demography in Ireland

### Key Points

- Ireland's population has increased by 23% since 1981. By 2036, the number aged  $\geq 35$  years and over is expected to increase by 51%-94%.
- COPD prevalence increases markedly with age.
- Females outnumber males in the older age groups. COPD is increasing amongst females as their smoking habits increase.
- The Irish Health Service needs to plan for the increasing burden of COPD, in light of current and projected demographic changes.

### 2.1 Introduction

Ireland's population is growing and ageing. Demographic changes have major health, social and personal implications in relation to the prevention, treatment and management of COPD. COPD prevalence increases with age, rising from approximately 10% in those aged 40-49 years to over 50% in those aged over 70.(3) Given current prevalence and projected demographic changes, the burden of disease due to COPD in Ireland will remain high.

### 2.2 Population Growth

Ireland's population is currently 4,239,848.(31) It increased by 23% since 1981 (3,443,405). Over the past 25 years the greatest growth rate occurred between 2002 (3,917,203) and 2006 (4,239,848) when the population increased by 8.2%. Changes were not similar throughout the country, for example:

- Dublin Mid-Leinster: 6.8% increase; (29% of the national population)
  - Dublin South 3.7% increase
  - Dublin Midlands 8.9% increase
- West: 7.5% increase; (24% of the national population)
  - Mid-West 6.3% increase
  - West/North-West 8.2% increase
- South: 7.8% increase; (25% of the national population)
  - South-East 8.8% increase
  - South 7.0% increase
- Dublin North-East: 11.6% increase; (22% of the national population)
  - Dublin North 9.8% increase
  - North-East 14.2% increase.

Source: CSO.

These population changes have implications for health service configuration and delivery, especially with respect to chronic diseases of high prevalence such as COPD.

## 2.3 Population Structure

Forty-nine per cent of the Irish population aged  $\geq 35$  years is male and 51% is female. This gender gap widens with increasing age. For those aged  $\geq 65$  years, 44% is male and 56% is female (Table 2.1). As COPD prevalence is increasing amongst women, it is important for health services to recognise the burden of illness caused by COPD and its co-morbidities and the importance of prevention and treatment.

**Table 2.1 Irish Population by Age Group and Gender, 2006**

| Age Group Years | Male      | Female    | Total     |
|-----------------|-----------|-----------|-----------|
| 0-34            | 1,130,790 | 1,088,830 | 2,219,620 |
| 35-44           | 315,249   | 308,185   | 623,434   |
| 45-54           | 262,533   | 259,280   | 521,813   |
| 55-64           | 205,504   | 201,551   | 407,055   |
| 65-74           | 127,435   | 135,113   | 262,548   |
| 75-84           | 64,815    | 92,535    | 157,350   |
| 85+             | 14,845    | 33,183    | 48,028    |
| Total           | 2,121,171 | 2,118,677 | 4,239,848 |
| Total 35+       | 990,381   | 1,029,847 | 202,0228  |

Source: CSO 2006

## 2.4 Life Expectancy

Life expectancy for both males and females has increased over the last century. Table 2.2 shows that in 2002 the average life expectancy at birth for males was 75.1 years and 80.3 years for females. In 2002 men aged 35 years, 65 years and 75 years could expect to live for another 42 years, 15 years and 9 years respectively. For women at similar ages (35 years, 65 years, 75 years) the life expectancy was 46 years, 19 years and 11 years respectively.

**Table 2.2 Life Expectancy in Ireland, 1926 and 2002**

| Age in years | 0    | 10   | 20   | 35   | 55   | 65   | 75  | 80  | 85  |
|--------------|------|------|------|------|------|------|-----|-----|-----|
| Males        |      |      |      |      |      |      |     |     |     |
| 1926         | 57.4 | 55.2 | 46.4 | 34.4 | 19.1 | 12.8 | 7.7 | 5.8 | 4.4 |
| 2002         | 75.1 | 65.7 | 56.0 | 41.8 | 23.4 | 15.4 | 8.9 | 6.5 | 4.6 |

| Females |      |      |      |      |      |      |      |     |     |
|---------|------|------|------|------|------|------|------|-----|-----|
| 1926    | 57.9 | 54.9 | 46.4 | 34.7 | 19.6 | 13.4 | 8.4  | 6.5 | 4.9 |
| 2002    | 80.3 | 70.8 | 60.9 | 46.2 | 27.4 | 18.7 | 11.2 | 8.2 | 5.8 |

Source: CSO 2004 Irish Life Tables No.14 2001-2003 & Census of Population 1926

In addition to longevity, it is important to both maintain and maximise quality of life. There are a number of measures to reflect quality of life, one of which is Disability Free Life Expectancy (DFLE). Table 2.3 shows Irish people's self assessment of quality of life in 2005. Other self assessment health measures are discussed in Chapter 3. At age 35 almost 71% of males and 68% of females said they had no disability. By 75 years of age this had reduced to 45% of males and 12% of females. Chronic diseases which increase with age, as exemplified by COPD and its co-morbidities, play a large role in reducing both quality of life and life expectancy. Among 25 EU countries surveyed in 2005, Ireland ranked ninth for males and seventh for females in descending order of DFLE at age 35 years.

**Table 2.3 Disability Free Life Expectancy (DFLE)\* as a Percentage of Life Expectancy (LE), Ireland 2005**

| Age | Males LE | Males DFLE % | Females LE | Females DFLE % |
|-----|----------|--------------|------------|----------------|
| 35  | 43.52    | 70.98        | 47.43      | 67.65          |
| 45  | 34.03    | 66.42        | 37.78      | 63.65          |
| 55  | 24.98    | 60.53        | 28.53      | 57.63          |
| 65  | 16.77    | 54.21        | 19.82      | 49.59          |
| 75  | 9.99     | 45.32        | 12.16      | 37.91          |
| 85  | 5.64     | 40.64        | 6.55       | 28.42          |

Source: European Health Expectancy Monitoring Unit (EHEMU).

\*"Disability free" is defined by a person's self-assessment of whether they are hampered in their daily activity by any ongoing physical or mental health problem, illness or disability (Statistics on Income & Living Conditions).

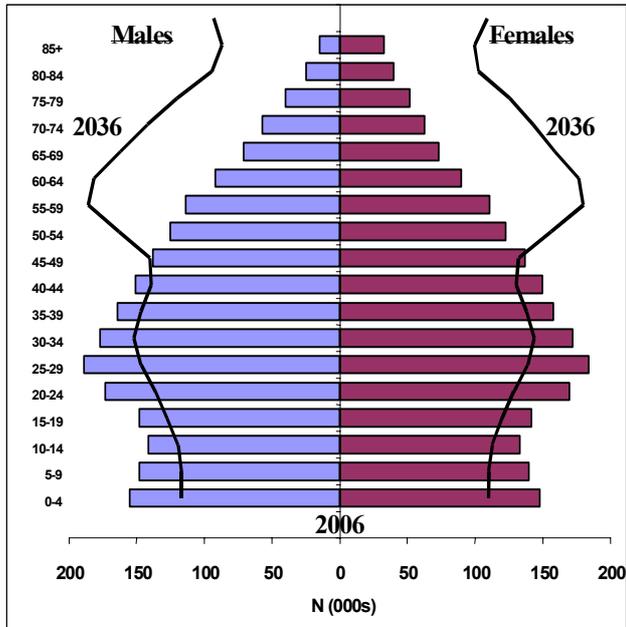
## 2.5 Population Projections

Ireland's population is ageing as well as growing. The population pyramids (Figures 2.1(a) and 2.1(b) show the actual population for 2006 and projected populations in 2036 by gender and age group (based on the two extremes of six assumption combinations). By 2036 the population forecasts range from 4.9 to 6.7 million. Major growth is expected in those aged 50 years and over.(32) Given the increasing prevalence of COPD with age, these age structure projections have major implications both for COPD numbers and their pressures on health service. (32)

**Figure 2.1(a) Actual and Projected Populations (Numbers in Thousands) by Gender and Age Group, Ireland, 2006 and 2036**

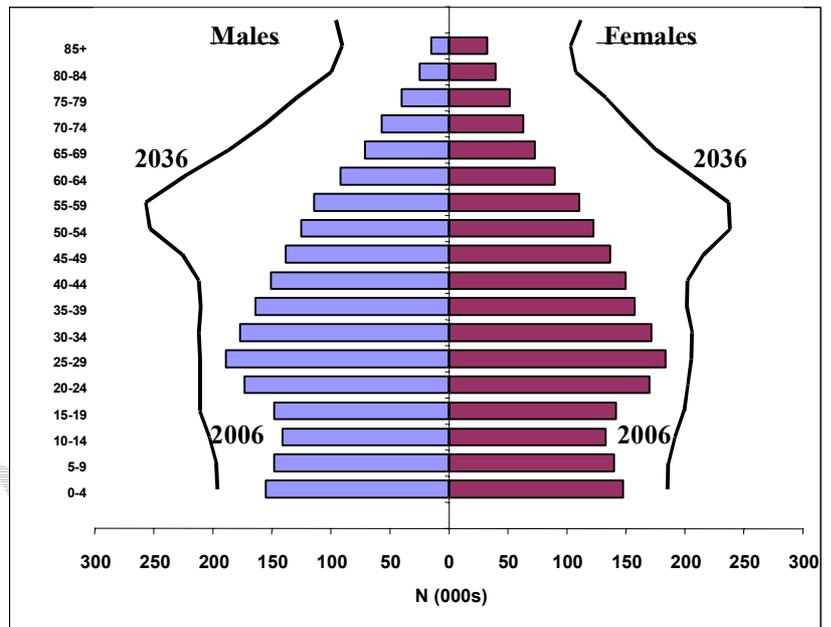
Lowest Outcome based on  
Combination of Zero Net Migration and  
Decreasing Fertility Assumptions  
(M0F2)

Figure 2.1(b) Actual and Projected  
Populations (Numbers in Thousands)



by Gender and Age Group, Ireland 2006  
and 2036

Highest Outcome based on  
Combination of High Net Inward  
Migration and Relatively High Fertility  
Assumptions (M1F1)



The population aged  $\geq 35$  years was 2,020,228 in 2006 but is expected to range from 3,059,882 (51% increase) to 3,914,531 (94% increase) by 2036 (Table 2.4). While greater percentage increases are expected at the upper end of the age scale (over 75s), much greater numbers will be aged between 35 and 65, i.e. in an age bracket where there is much potential for health gain through early diagnosis and management.

**Table 2.4 Actual and Projected Population Range based on M0F2 and M1F1 Assumption Combinations for Ages 35+, 2006 and 2036**

| Age Group | Male    |           |           |          |       | Female    |           |           |          |       |
|-----------|---------|-----------|-----------|----------|-------|-----------|-----------|-----------|----------|-------|
|           | 2006    | 2036      |           | % Change |       | 2006      | 2036      |           | % Change |       |
|           |         | M0F2      | M1F1      | M0F2     | M1F1  |           | M0F2      | M1F1      | M0F2     | M1F1  |
| 35-44     | 315,249 | 278,191   | 424,277   | -11.8    | 34.6  | 308,185   | 261,193   | 403,726   | -15.2    | 31.0  |
| 45-54     | 262,533 | 325,480   | 506,193   | 24.0     | 92.8  | 259,280   | 312,566   | 477,781   | 20.6     | 84.3  |
| 55-64     | 205,504 | 363,175   | 447,494   | 76.7     | 117.8 | 201,551   | 352,766   | 412,109   | 75.0     | 104.5 |
| 65-74     | 127,435 | 283,937   | 312,833   | 122.8    | 145.5 | 135,113   | 286,574   | 307,594   | 112.1    | 127.7 |
| 75-84     | 64,815  | 188,905   | 199,587   | 191.5    | 207.9 | 92,535    | 205,784   | 215,023   | 122.4    | 132.4 |
| 85+       | 14,845  | 92,608    | 95,530    | 523.8    | 543.5 | 33,183    | 108,703   | 112,384   | 227.6    | 238.7 |
| Total 35+ | 990,381 | 1,532,296 | 1,985,914 | 54.7     | 100.5 | 1,029,847 | 1,527,586 | 1,928,617 | 48.3     | 87.3  |

Source: CSO, Population and Labour Force Projections, 2011-2041.

## 2.6 Conclusion

Ireland's ageing and growing population has implications for health planning. While increasing life expectancy is an indicator of better health and social conditions, it brings with it the challenge of diseases such as COPD whose prevalence increase with age. The proportion of persons aged over 35 emphasises the priority which is needed to deal with COPD. As a chronic disease, COPD and its co-morbidities exerts a major impact both on people's health and on health services. Projected population changes highlight the need for an integrated approach to care of people with COPD.

## Chapter 3 Burden of Illness

### Key Points

- Respiratory disease<sup>1</sup> kills one person in five in Ireland.
- Ireland has the highest death rate from respiratory disease in the European Union - death rates are over twice the EU average. Within Europe, only Kyrgyzstan has a death rate from respiratory disease higher than Ireland.
- COPD and pneumonia accounted for 80% of respiratory deaths (excluding lung cancer) in 2006.
- Social inequality is linked with a higher proportion of deaths from respiratory disease, especially COPD, than any other body system. A similar picture is seen with morbidity.
- Respiratory ill-health is the third most frequently reported illness in adults. It significantly hampers peoples' daily lives.
- Available data under-estimates the burden of respiratory disease in Ireland, in particular COPD.
- Prevalence of COPD amongst Irish young adults (20-44 years) is higher than European counterparts.
- Respiratory consultations account for 14.5% of GP visits among those with GMS eligibility. A significant number of COPD exacerbations are treated by Primary Care.
- Respiratory disease (including lung cancer) accounts for 5.7% of inpatient discharges and 12.4% of bed days used.
- Drug prescription rates for respiratory disease are among the highest for any body system.
- Respiratory disease cost in excess of €824 million in 2006, of which the cost to the Irish Health service was in excess of €437 million.

### 3.1 Introduction

The aim of this chapter is to describe the health (mortality and morbidity) impact of respiratory disease **Error! Bookmark not defined.** including COPD and its costs. It highlights disease trends and inequalities in respiratory health.

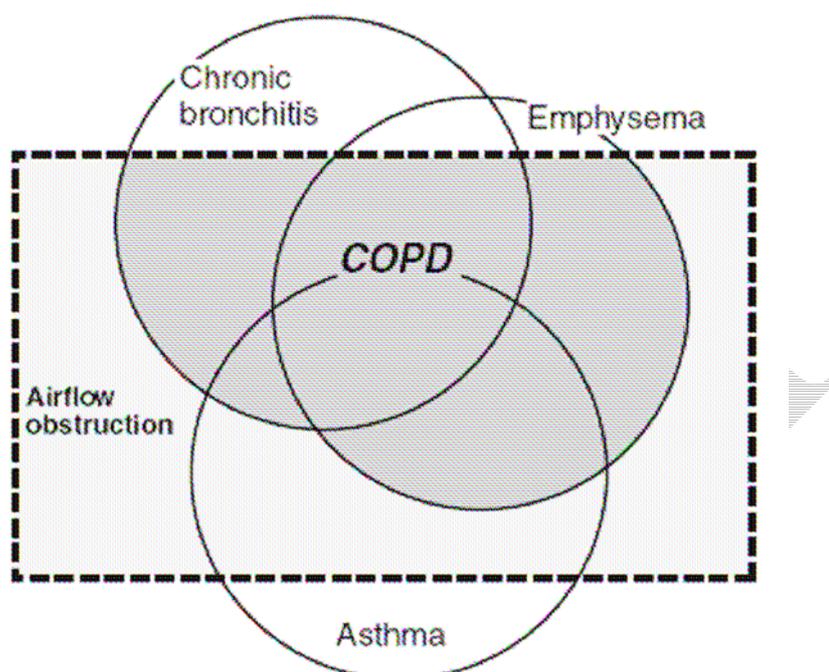
COPD is the term used for conditions in patients with irreversible airflow obstruction who previously would have been diagnosed as having chronic bronchitis or emphysema. COPD is

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<sup>1</sup> Except where otherwise indicated, the term 'respiratory disease' refers to all diseases of the respiratory system and includes lung cancer

the umbrella term for a number of chronic lung disorders, including chronic bronchitis, emphysema, chronic obstructive airway disease and chronic airway flow limitation which is best visualised in the Venn diagram in Figure 3.1 below.

**Figure 3.1 Overlap of bronchitis, emphysema and asthma within chronic obstructive pulmonary disease (COPD)(22)**



The non-proportional Venn diagram shows the overlap of chronic bronchitis, emphysema and asthma within COPD. Chronic bronchitis, airway narrowing and emphysema are independent effects of cigarette smoking, and may occur in various combinations. Asthma is associated with reversible airflow obstruction. Patients with asthma whose airflow obstruction is completely reversible do not have COPD. In many cases it is impossible to differentiate patients with asthma whose airflow obstruction does not remit completely from persons with chronic bronchitis and emphysema who have partially reversible airflow obstruction with airway hyper-reactivity.

As a chronic respiratory illness COPD is characterised by progressive, partially reversible airflow obstruction. The main symptoms, which are usually insidious in onset, are shortness of breath and activity limitation. As the disease progresses, frequent respiratory exacerbations become the norm.(33, 34) Systemic manifestations of advanced disease include skeletal muscle dysfunction,(35) right heart failure,(36) secondary polycythaemia,(37) depression(38) and altered nutrition.(39)

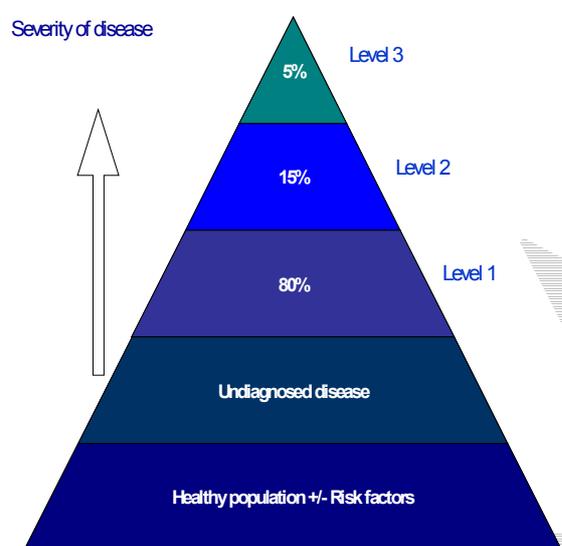
The health impact of COPD as a chronic disease is shown in Figures 3.2(a) and (b). In Figure 3.2 the base of the pyramids represents the general population who do not have COPD. Their priority is prevention. Then there are a large number of undiagnosed people who require accurate and timely diagnosis and intervention. The narrowing of the pyramid represents the different behaviours of COPD and the health needs of patients. Those with diagnosed disease are represented on three levels:

**Level 1:** People with COPD which is well controlled by the patient with primary health care support (approximately 80% of patients)

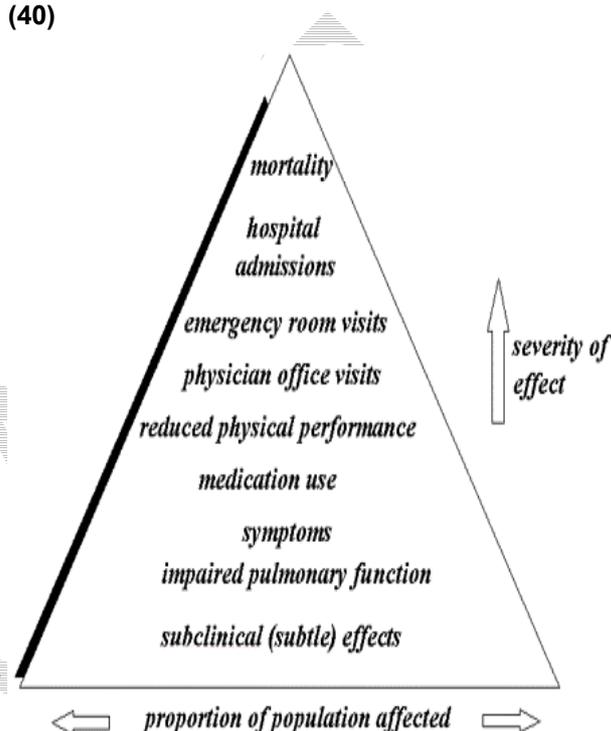
**Level 2:** People with more complex COPD of varying severity with or without other co-morbidities (approximately 15% of patients)

**Level 3:** People with complex conditions, often with complications that require specialist care, intensive intervention and are at high risk of hospitalisation (approximately 5% of patients).

**Figure 3.2 (a)**  
**Manifestation of Chronic Illness and COPD in a Population (24)**



**Figure 3.2 (b)**  
**How COPD fits into the chronic disease model (40)**



Data from the second INHALE report show that respiratory disease, and COPD in particular, has a serious effect on people's health, the health services and the wider economy.(30)This strategy document uses health data from that INHALE report which focused on the year 2004. Where possible this data was updated to reflect the 2006 situation. Irish health information systems do not fully capture the burden of illness due to respiratory disease.

As people who have asthma move into middle age it is likely that there is some element of irreversible airflow obstruction. Therefore COPD is more likely to be the correct diagnosis for those aged  $\geq$ . This fact is not always realised by patients nor recorded and reflected in data systems such as Hospital Inpatient Enquiry (HIPE).

## 3.2 Mortality

One in five Irish people dies from respiratory disease.<sup>2</sup> (41) In healthy adults, pneumonia and influenza do not generally cause death. For people with COPD, pneumonia and influenza are more common. They can be the event which can triggers an exacerbation, necessitating hospital admission and contributing to death. Hence, when considering the burden of COPD, data for pneumonia and influenza need to be taken into consideration. As both COPD and lung cancer are largely caused by smoking, data on lung cancer rates and trends help build a more complete picture of COPD. Mortality data presented here includes international comparisons, Irish figures, trends over recent years within Ireland and socio-economic variation.

### 3.2.1 International comparisons

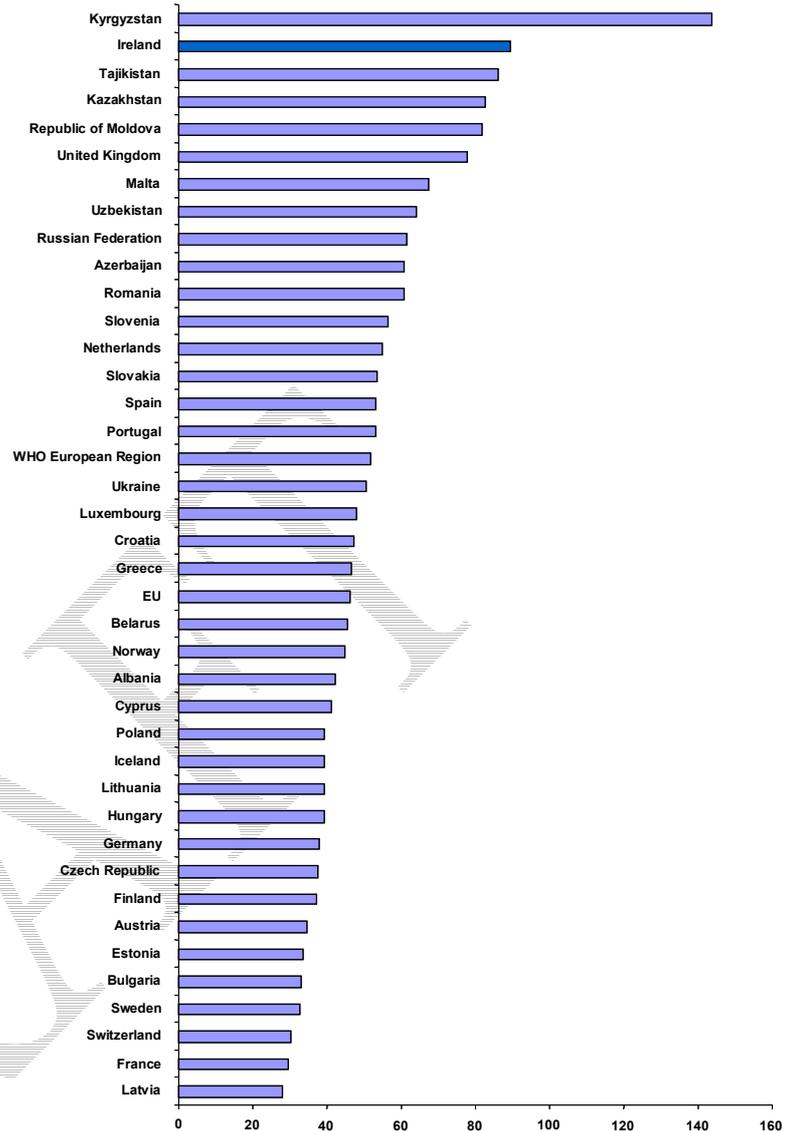
Among the countries of the World Health Organisation (WHO) European Region, only Kyrgyzstan has a death rate from respiratory disease (excluding lung cancer) higher than Ireland. Within the EU, only the UK, with a mortality rate of 78/100,000 (males 95, females 67), approaches the Irish rate of 89/100,000 (males 112, females 74) (Table 3.1, Figure 3.3).

**Table 3.1 and Figure 3.3 Age-standardised death rates per 100,000 population from diseases of the respiratory system by sex, 2004, selected European countries(4)**

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<sup>2</sup> Except where otherwise indicated, the term 'respiratory disease' refers to all diseases of the respiratory system and includes lung cancer

|                     | Men        | Women     | All       |
|---------------------|------------|-----------|-----------|
| Albania             | 54         | 32        | 42        |
| Austria             | 52         | 25        | 35        |
| Azerbaijan          | 75         | 50        | 61        |
| Belarus             | 93         | 19        | 45        |
| Bulgaria            | 48         | 21        | 33        |
| Croatia             | 75         | 31        | 47        |
| Cyprus              | 56         | 31        | 41        |
| Czech Republic      | 55         | 26        | 37        |
| Estonia             | 67         | 14        | 33        |
| Finland             | 60         | 24        | 37        |
| France              | 44         | 21        | 30        |
| Germany             | 56         | 27        | 38        |
| Greece              | 55         | 40        | 47        |
| Hungary             | 59         | 26        | 39        |
| Iceland             | 40         | 39        | 39        |
| <b>Ireland</b>      | <b>112</b> | <b>74</b> | <b>89</b> |
| Kazakhstan          | 142        | 47        | 82        |
| Kyrgyzstan          | 201        | 104       | 144       |
| Latvia              | 54         | 12        | 28        |
| Lithuania           | 78         | 17        | 39        |
| Luxembourg          | 79         | 32        | 48        |
| Malta               | 98         | 47        | 67        |
| Netherlands         | 80         | 41        | 55        |
| Norway              | 59         | 36        | 45        |
| Poland              | 65         | 24        | 39        |
| Portugal            | 76         | 37        | 53        |
| Republic of Moldova | 133        | 48        | 82        |
| Romania             | 87         | 40        | 61        |
| Russian Federation  | 120        | 27        | 61        |
| Slovakia            | 82         | 36        | 53        |
| Slovenia            | 91         | 38        | 56        |
| Spain               | 84         | 33        | 53        |
| Sweden              | 41         | 27        | 33        |
| Switzerland         | 44         | 21        | 30        |
| Tajikistan          | 103        | 76        | 86        |
| Ukraine             | 99         | 21        | 51        |
| United Kingdom      | 95         | 67        | 78        |
| Uzbekistan          | 77         | 54        | 64        |
| WHO European Region | 81         | 33        | 52        |
| EU before May 2004  | 66         | 34        | 47        |



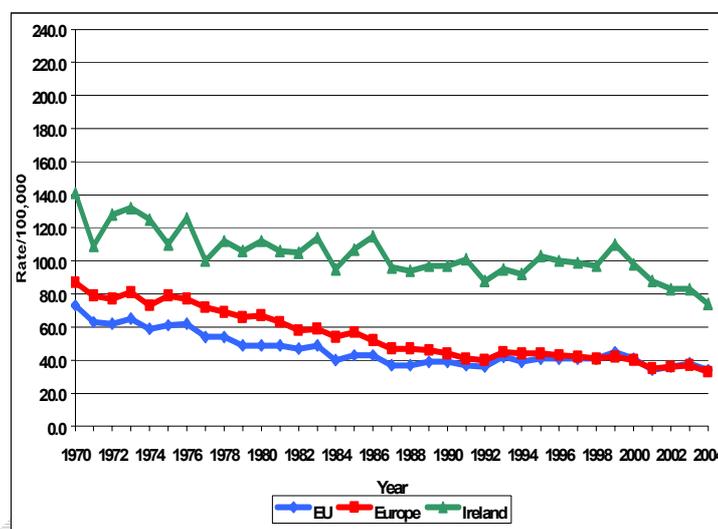
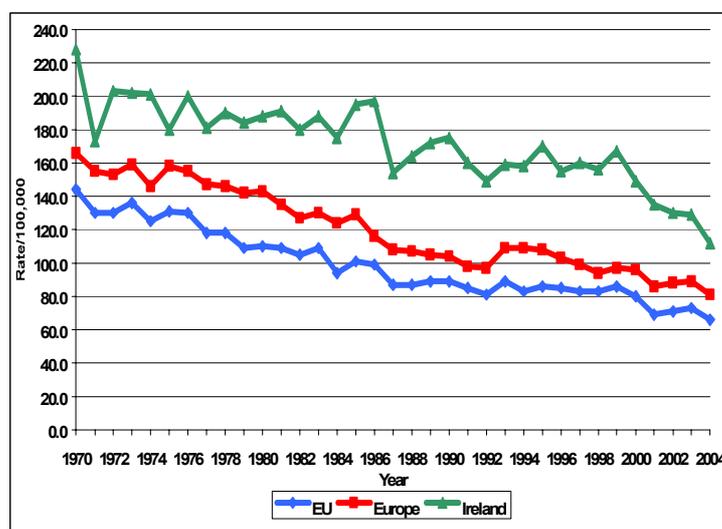
In fact, death rates from respiratory disease (excluding lung cancer) in Ireland are almost double the EU average.(4) The difference in rates between Ireland and other EU countries is particularly marked for women – Ireland 74/100,000, EU average 34/100,000. In France (21/100,000) and Switzerland (21/100,000) death rates from respiratory disease in women are less than a third of the rate among Irish women (Table 3.1).

WHO data show that between 1970 and 2004, death rates from respiratory disease (excluding lung cancer) fell by 56% in Europe, 53% in the EU and 51% in Ireland. The decrease in rates for Irish females (48%) was less than that for their male counterparts (51%), Figure 3.4.

**Figure 3.4 Age-Standardised Death Rates per 100,000 Population from Diseases of the Respiratory System (excluding lung cancer), EU, Europe and Ireland, 1970-2004**

**Male**

**Female**



Source: World Health Organisation (2007) European Health for All Database (3).

Diseases of the Respiratory System are defined as ICD-10 Codes J00-J99.

### 3.2.2 Mortality in Ireland

In 2006, there were 5,586 deaths due to respiratory diseases<sup>3</sup> in Ireland which accounted for 20% of all deaths. This exceeds deaths from coronary heart disease deaths (4,860, 18% of all deaths). The excess was most marked among women where death from respiratory disease is the second highest cause of death (21%) after non-respiratory cancer (23%).

Of the 5,586 deaths in 2006 from respiratory diseases:

- 29% (1,608) were due to lung cancer
- 34% (1,914) were due to pneumonia and influenza
- 23% (1,289) were due to COPD.

Pneumonia, as previously mentioned, is often a complicating co-morbidity of an underlying condition such as COPD.

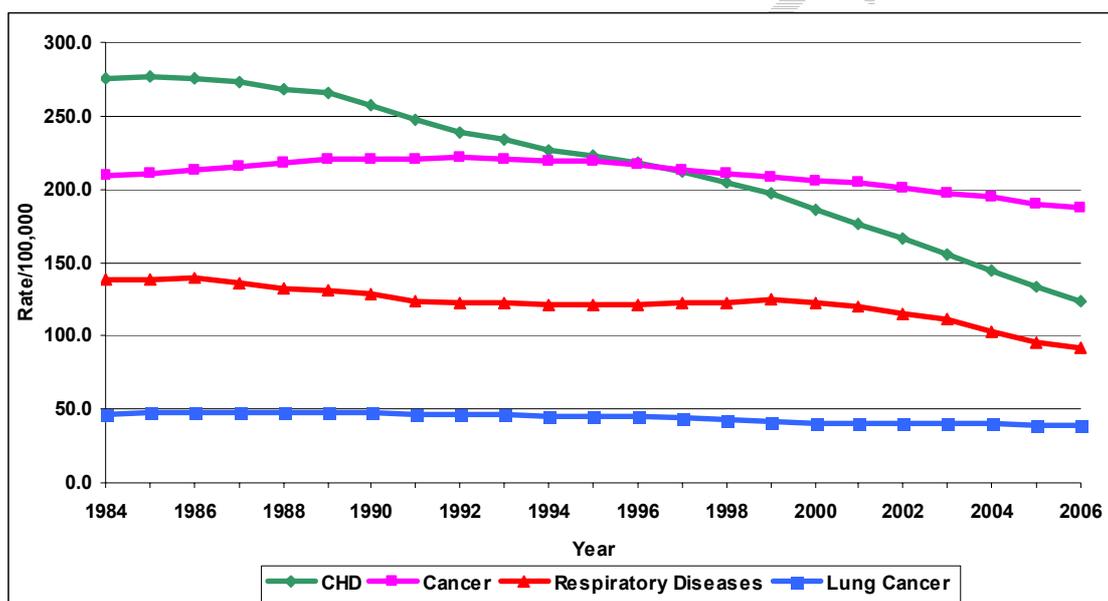
Figures for lung cancer are relevant given the shared risk factor with COPD of smoking. In 2006, lung cancer accounted for 20% of all cancer deaths (17% females, 23% males). The number of women in Ireland dying from lung cancer (642) is approaching the number dying from breast cancer (667). Given the changed smoking patterns of women the number of deaths from lung cancer is expected to exceed that from breast cancer in the near future.

### 3.2.3 Trends in death rates in Ireland

<sup>3</sup> Except where otherwise indicated, the term 'respiratory disease' refers to all diseases of the respiratory system and includes lung cancer

Between 1984 and 2006, there were statistically significant downward trends in death rates from coronary heart disease (CHD), cancer (includes lung), respiratory disease (excluding lung cancer) and lung cancer as shown in Figure 3.5. The annual average fall in rates for CHD was 3.5% while that for respiratory diseases was 1.4%. COPD and pneumonia accounted for 80% of all respiratory deaths, excluding lung cancer. Lung cancer rates fell by an average of 1.1% annually.

**Figure 3.5 Age-standardised death rates per 100,000 population from respiratory diseases (excluding lung cancer), CHD, all cancers (includes lung cancer) and cancer of the lung, Ireland, 1980-2006 (5 year moving average)**



Source: PHIS, Version 10 beta

Figure 3.6 shows that male deaths rates for CHD, Cancer (all), respiratory disease and lung cancer were consistently higher than for females between 1980-2006 but the rate of decline for males was generally greater. With the exception of female lung cancer deaths (which increased by a significant 0.2% annually), downward trends were observed for each cause and gender:

CHD: Male 3.6% decrease annually; Female 3.2% decrease annually

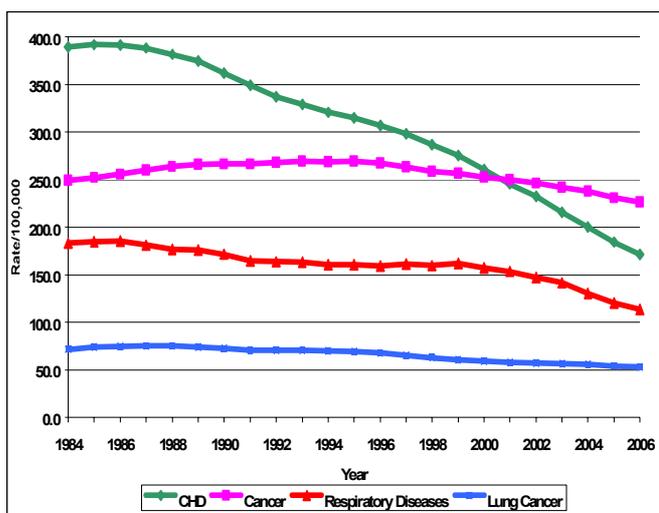
Cancer (all): Male 0.4% decrease annually; Female 0.6% decrease annually

Respiratory Diseases (excluding lung cancer): Male 1.7% decrease annually; Female 0.9% decrease annually

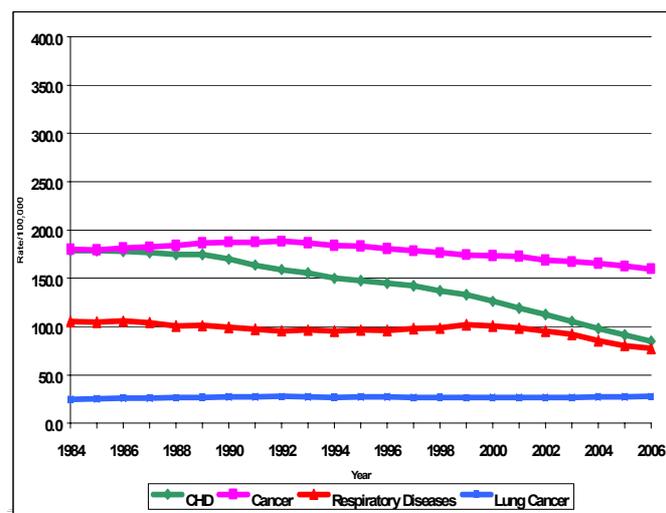
Lung Cancer: Male 1.7% decrease annually; Female 0.2% increase annually

**Figure 3.6 Male and Female Age-standardised death rates per 100,000 population from respiratory diseases (excluding lung cancer), CHD, all cancers and cancer of the lung, Ireland, 1980-2006 (5 year moving average)**

## Male



## Female



Source: PHIS, Version 10 beta

The significant decrease in CHD mortality can be attributed to lifestyle changes and improved treatment.(42) The same could be achieved for respiratory health.

### 3.2.4 Socio-economic variation

Death from respiratory disease<sup>4</sup>, especially COPD, is a marker of socio-economic differences. These differences are more marked for respiratory disease mortality than for mortality in general. This difference has been quantified by the Institute of Public Health in Ireland where the all cause mortality rate in the lowest occupational class was 100-200% higher than in the highest occupational class.(43) Differences existed for nearly all of the main causes of death but respiratory diseases, with a difference of 200%, had the widest occupational class difference. Updated analysis for respiratory data (2002-2006) confirms this for respiratory disease deaths. As evident from Table 3.1, COPD and lung cancer deaths showed the most marked social class differentials.

**Table 3.2 Standard mortality rates (per 100,000) by selected diseases of the respiratory system and social class, men of working age, 2002 - 2006, Republic of Ireland**

| Social Class | Cancer of the larynx, trachea, bronchus, lung | Pneumonia | COPD | Asthma | All Respiratory |
|--------------|---|-----------|------|--------|-----------------|
| Upper        | 10.2  | 2.1       | 1.3  | 0.3    | 7.8             |
| Middle       | 34.1  | 4.7       | 3.7  | 1.0    | 12.5            |
| Lower        | 24.6  | 4.0       | 6.9  | 0.6    | 13.7            |

<sup>4</sup> Except where otherwise indicated, the term 'respiratory disease' refers to all diseases of the respiratory system and includes lung cancer

|   |      |      |      |      |      |
|---|------|------|------|------|------|
| Unknown   | 53.6 | 17.4 | 8.6  | 0.9  | 36.1 |
| *Excess Mortality Rate in Lowest Social Class compared to Highest | 141% | 90%  | 415% | 110% | 76%  |

Source: Central Statistics Office

Data Analysis: Strategic Health Planning & Evaluation, Population Health Directorate, HSE.

\* Excess Annual Directly Standardised Mortality Rate in lowest Class compared to highest. As the Socio-Economic Group (SEG) classification system used for deaths does not match the SEG system used for censuses 2002 and 2006, the Social Class system was used as a proxy.

### 3.3 Morbidity

COPD is responsible for a substantial burden of physical illness and social and economic consequences for the patient, families, carers and the health services. In this section morbidity is discussed in relation to self-reported illness, international comparisons, socio-economic aspects and health service data from primary and secondary care.

The health care requirements of people with COPD can vary depending on disease severity (see pyramid, Figure 3.2). The aim is to sustain maximum health status and minimise exacerbations so that health care and support can be maintained at the lowest possible level of complexity. Morbidity data includes visits to GPs and Emergency Departments, hospitalisations, work days lost and self-reported illness. Irish morbidity data relies to a large extent on HIPE (hospitalisations). A comprehensive picture of COPD morbidity is not possible as the majority of people with COPD do not require hospitalisation.

The under-diagnosis of COPD, and the likelihood that some self-reported asthma in those aged  $\geq 35$  years is actually COPD, limits the usefulness of data, particularly that within the community setting. In addition, morbidity from COPD may be affected by other co-morbid chronic conditions which are not directly related to COPD but which either impact on the patient's health status, or interfere with COPD management. The lack of comprehensive morbidity data, not only for COPD but for many chronic diseases, is a factor which limits both the systematic assessment of need and the development of appropriate services.

#### 3.3.1. Self-reported respiratory illness in adults

In the previous chapter, the impact of chronic diseases on Disability Free Life Expectancy was mentioned. The Quarterly National Household Survey (QNHS) produces quarterly labour force estimates and conducts special modules on different social topics. These have provided useful information on the level of morbidity associated with respiratory disease including COPD. A number of key results from various modules (2001: module on health,(9) 2002:

module on disability,(44) 2004: module on disability update(45)) are presented in Tables 3.3 and 3.4 below.

**Table 3.3 Self-reported respiratory illness in adults**

|  |  |
|--|--|
| 2001: module on health                         | 6.4% of adults (aged $\geq 18$ yrs) reported chronic airways disease.  |
| 2002: module on disability in the labour force | 41,500 reported chest and breathing problems, <ul style="list-style-type: none"> <li>• 39.3% (16,300) reported problems &gt; 10 yrs duration</li> <li>• 14.5% (6,000) problems of 5-10 yrs duration</li> </ul> |
| 2004: module on disability update              | 11% (298,300) 15 to 64 yr olds had a health problem of $\geq 6$ months duration.   |

**Table 3.4 Respiratory Illness and the labour force**

|  |  |
|--|--|
| 2002: module on disability in the labour force | Of those with “chest or breathing problems”, 18,300 had some restriction on the kind of work and 15,600 the amount of work they could do (these groups are not mutually exclusive). Similarly, of those in employment 5,800 had restrictions in kind and 4,400 restrictions on the amount of work they could do. |
| 2002: module on disability in the labour force | Of those in employment with health problems, respiratory problems accounted for a variable percentage of these problems depending on employment status, NACE * economic sector and occupational groups.  |
| 2004: module on disability update              | 17% (18,600) of those in employment with a long-term illness or disability (110,800) reported chest or breathing problems, second in frequency only to musculoskeletal disorders   |

\* The European industrial activity classification

On average 17% of those in employment with health problems report “breathing” problems (Table 3.4). Some groups report lower rates, e.g. 10% among self-employed with paid employees, while higher rates are reported in workers in sales (28%) and hotels and restaurants (29%).(45)

As part of the Living in Ireland Survey (LIIS) in 2001, 6,518 individuals were surveyed by the ESRI. (46) Respiratory disease was the third most frequently reported illness:

- Twenty per cent of respondents reported “health problems”.
- Of these, 14.5% reported respiratory disease as their first, second or third illness, with the majority 164 (12.2%) reporting it as their principal illness.
- All of those with respiratory disease described their condition as chronic.
- The mean length of time that respondents reported having the disease was 16 years.
- Sixty six percent reported being hampered in their daily life by their disease.

### 3.3.2 International comparisons of self-reported respiratory illness

A comparison of COPD rates between different countries can be of limited value due to different diagnostic terms, different definitions and different methods of collecting data.

In a 2001 European survey on chronic bronchitis and smoking habits in those aged 20-44 years, Ireland had a prevalence of chronic bronchitis at 8% versus a median prevalence of 2.6%. Approximately 45% of Irish respondents were current smokers (females 46.5%, males 44.2%).(8) While the age group surveyed does not represent the usual age profile of COPD patients, it does indicate however that COPD will continue to be a significant problem in Ireland, given both the prevalence of symptoms and of smoking. It seems unlikely that mortality from COPD in Ireland will fall even in the medium term and that Ireland will continue to have one of the highest mortality rates from this disease.(47)

Another international survey which included Ireland supports the evidence that COPD develops earlier than is usually believed and that Ireland has a high rate.(48) Ireland was amongst five countries where the prevalence of moderate COPD in 20-44 year olds was 5% or higher.

### 3.3.3 Socio-economic factors and morbidity

In 1996, Lyons et al reported a prevalence of 6.2% for chronic bronchitis among 2,703 Irish GP attendees aged 40-69. The relative rate among persons from social classes 5 and 6 was 3.89 times that in persons from social classes 1 and 2.(49)

Among homeless men in Dublin aged 40-45 years (78% of whom smoked) 13% had “bronchitis”, 20% used inhalers, 53% were wheezy and 45% had ongoing cough.(7)

### 3.3.4 Primary Care

The 2001 “Living in Ireland Survey” found that 92% of those with a respiratory illness had attended a GP at least once in the preceding 12 months compared with 73% (6,500) of all those interviewed.(46) Data on frequency of visits as outlined in Table 3.5 indicate clearly that those with respiratory disease were both more likely than others to visit a GP at least once a year and more likely to do so on a number of occasions.

**Table 3.5 GP visits by patients with respiratory disease, 2001.(46)**

| Number of GP Visits | Respiratory Disease as Principal Illness |              | Total with Respiratory Disease |              | Total Surveyed |              |
|---------------------|--|--------------|--------------------------------|--------------|----------------|--------------|
|                     | Patients                                 | Total visits | Patients                       | Total visits | Patients       | Total visits |
| 0                   | 15 (9%)                                  | 0            | 16 (8%)                        | 0            | 1764 (27%)     | 0            |
| 1-4                 | 68 (42% )                                | 182          | 77 (40%)                       | 216          | 3304 (51%)     | 7,171        |

|       |          |      |          |       |           |        |
|-------|----------|------|----------|-------|-----------|--------|
| 5-9   | 35 (22%) | 223  | 37 (19%) | 236   | 722 (11%) | 4,412  |
| 10+   | 45 (28%) | 1080 | 64 (33%) | 1377  | 700 (11%) | 12,219 |
| Total | 163      | 1485 | 194      | 1,829 | 6,500     | 23,802 |

The Primary Care Reimbursement Service (PCRS) reported that in 2006, 14.5% of all GP consultations were for respiratory disease. This is similar to UK data.<sup>(50)</sup> Among people aged  $\geq 35$  years eligible for medical cards, and on treatment consistent with a diagnosis of COPD in 2006, approximately 18,000 people (in this category) were prescribed an antibiotic by their GP. This can be used as an indicator of the number of COPD exacerbations treated in primary care. (This statistic is based on the analysis by NCPE see Technical Reports).

There is no comprehensive Irish data on the reasons people attend a GP. Therefore reliable data on the number of COPD/ respiratory consultations in primary care is not available. The paucity of data in this area contrasts with the reality that the majority of those with respiratory disease, especially a chronic disease such as COPD, are and should be managed in Primary Care.

### 3.3.5 Hospitalisations

The hospital activity data presented here is based on in-patient and day case data from HIPE. It does not take account of Primary Care and out-patient consultations. As COPD is largely a disease of those aged over 35, a decision was made to limit analysis of COPD hospital data to this age group. While this may slightly under-estimate COPD figures (by 2%), it provides a clearer view of the impact of COPD on hospital usage by those in middle and old age. The acute hospital data presented is as follows:

- a) Hospitalisations for common conditions including respiratory disease (all ages)
- b) COPD hospitalisations trends between 1997-2006 ( $\geq 35$  years)
- c) 2006 in-patient hospitalisation data for respiratory disease and COPD i.e. type of admission, age profile, case complexity, ventilation needs, co-morbidity and repeat admissions ( $\geq 35$  years).

#### a) Hospitalisations in 2006 for common conditions including respiratory disease

Table 3.6 shows hospitalisations for diseases of the circulatory and respiratory systems, all cancers and lung cancer and all diseases in 2006. Respiratory disease<sup>5</sup> accounted for 70,009 hospitalisations (64,020 Diseases of the Respiratory system (excluding lung cancer), 5,989 Lung Cancer) i.e. 5.7% of the 1.2 million hospitalisations in Irish hospitals that year. Inpatient respiratory activity accounted for 12.4% of total bed days used (BDU). This resulted in a higher than average length of stay (LOS) of 7.2 days (versus overall average of 6.3 days).

<sup>5</sup> Except where otherwise indicated, the term 'respiratory disease' refers to all diseases of the respiratory system and includes lung cancer

**Table 3.6 Activity in HIPE-Reporting Hospitals by Principal Diagnosis and Case type, All Ages, Ireland, 2006\***

| Principal Diagnosis<br>(ICD-10 AM Codes)                                    | Total Discharges | Inpatient Discharges |                |             | Day Cases    |
|---|------------------|----------------------|----------------|-------------|--------------|
|   | N                | N                    | BDU<br>N       | Mean<br>LOS | N            |
| Diseases of Circulatory System<br>including CHD (I00-I99)                   | 71,632           | 52,326               | 531,356        | 10.2        | 19,306       |
| Coronary Heart Disease (I20-I25)  | 23,212           | 17,577               | 132,199        | 7.5         | 5,635        |
| <b>Diseases of Respiratory System<br/>(J00-J99) (excluding lung cancer)</b> | <b>64,020</b>    | <b>59,255</b>        | <b>409,506</b> | <b>6.9</b>  | <b>4,765</b> |
| <b>Lung Cancer (C33-C34)</b>  | <b>5,989</b>     | <b>3,307</b>         | <b>43,384</b>  | <b>13.1</b> | <b>2,682</b> |
| All cancers excluding Lung cancer<br>(C00-C32, C37-C96)                     | 69,323           | 27,878               | 341,195        | 12.2        | 41,445       |
| All Other Diagnoses   | 323,590          | 160,351              | 939,798        | 5.9         | 163,239      |
| All Diagnoses   | 1,234,149        | 578,628              | 3,644,684      | 6.3         | 655,521      |

Source: HIPE & NPRS Unit, ESRI. \* excludes non-residents and 'no fixed abode' cases.

**b) COPD hospitalisation trends: 1997-2006**

The numbers of hospitalisations for COPD in persons aged 35 years or older over the ten-year period from 1997 to 2006 inclusive ranged from a minimum of 7,479 in 2001 to a maximum of 11,333 for 2006 (Table 3.7).

**Table 3.7 Numbers of COPD Hospitalisations (Principal Diagnosis) in Public HIPE-Reporting Hospitals in Ireland for Ages 35+ by Casetype, 1997-2006\***

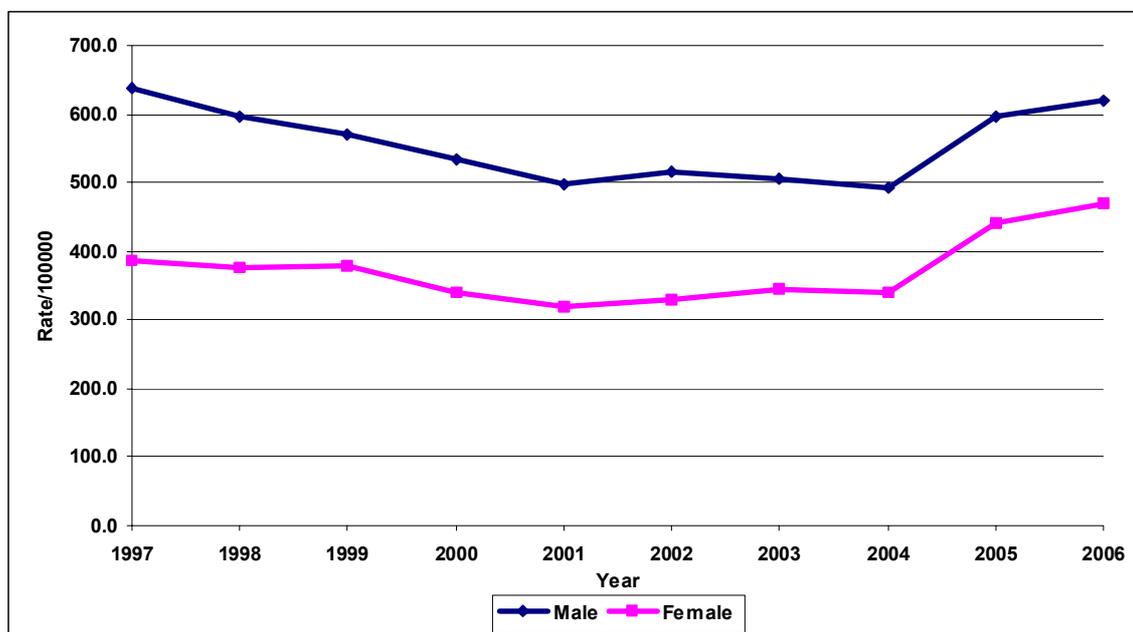
| Year | Inpatient Discharges | Day Cases | Total |
|------|----------------------|-----------|-------|
| 1997 | 8651                 | 282       | 8933  |
| 1998 | 8255                 | 281       | 8536  |
| 1999 | 8134                 | 322       | 8456  |
| 2000 | 7556                 | 300       | 7856  |
| 2001 | 7200                 | 279       | 7479  |
| 2002 | 7508                 | 394       | 7902  |
| 2003 | 7523                 | 537       | 8060  |
| 2004 | 7724                 | 415       | 8139  |
| 2005 | 9924                 | 554       | 10478 |
| 2006 | 10712                | 621       | 11333 |

Source: HIPE & NPRS Unit, ESRI. \* excludes non-resident and 'no fixed abode' cases.

Figure 3.7 shows that age-standardised discharge rates for males were consistently higher than for females. No significant time trends were evident for either males or females as early decreases/fluctuations were followed by substantial increases since 2004. Indeed, the female

rate for 2006 is the highest ever recorded over the time period. (It should be noted that ICD 10 coding was introduced in 2005 along with new coding guidelines and standards.)

**Figure 3.7 Age-Standardised Hospitalisations Rates with COPD as Principal Diagnosis for Ages 35+ by Gender, 1997-2006**

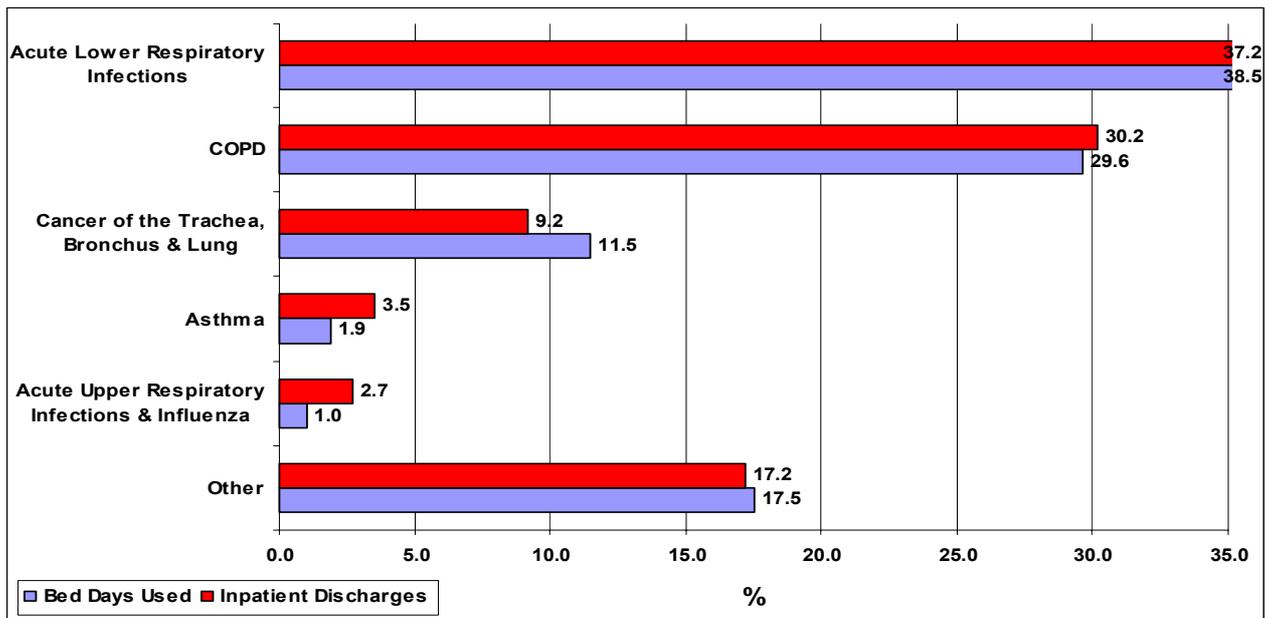


**c) Inpatient hospitalisation data for patients with respiratory disease and COPD (2006)**

In 2006, nearly one third of both respiratory inpatient discharges (29%) and bed days used (30%) related to COPD. Given that many of those with lower respiratory infections will have COPD as an underlying diagnosis (12%), it was the dominant respiratory inpatient disease for persons aged 35 years or older. This is shown in Figure 3.8.

**Figure 3.8 Respiratory Diseases<sup>6</sup>2006: Proportion of Inpatient Discharges and Bed Days Used by Diagnosis for Ages 35+**

<sup>6</sup> ICD-10 AM C33-C34, J000-J99

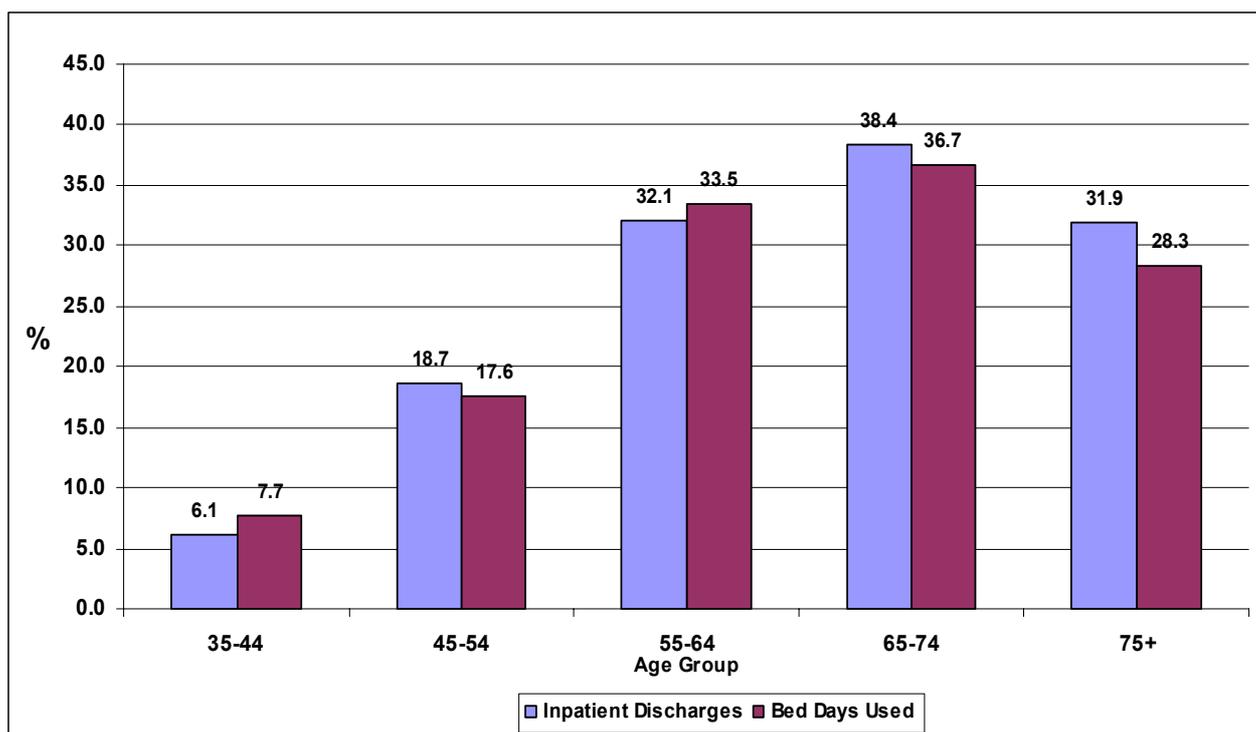


Of the 13,199 inpatient hospitalisations aged 35+ years with acute lower respiratory infections as principal diagnosis in 2006, 12% (1,525) had COPD recorded as an additional diagnosis. Of all 333,052 inpatient discharges aged 35+ in 2006 (irrespective of principal diagnosis), 3% (10,127) had COPD as an additional diagnosis. This is in addition to the 3.2% (10,712) who had it as a principal diagnosis.

Of the 10,712 inpatient hospitalisations aged 35+ in 2006 with COPD as a principal diagnosis, 10,111 (94%) were emergency admissions. Of the 1,525 (12%) acute lower respiratory infection cases with COPD as additional diagnosis, 1,490 (98%) were emergency admissions.

COPD inpatient activity as a proportion of respiratory diseases varied with age, as evident from Figure 3.9. Discharge proportions increased from 6% in the 35-44 age group to 38% in the 65-74 age group and decreased thereafter. The same pattern was evident for bed days used.

**Figure 3.9 COPD Inpatient Discharges and Bed Days Used as a Proportion (%) of All Respiratory Diseases by Age Group, 2006**



Of those hospitalised as inpatients with COPD in 2006, 91% had additional co-morbidities. Co-morbidities may influence the need for hospitalisation. The top 10 diseases recorded as second diagnoses, which accounted for over half of the cases (54%), are shown in Table 3.8. As can be seen, the majority of co-morbidities were either respiratory or cardiac.

**Table 3.8 Number and Percentages of COPD Inpatient Cases (Principal Diagnosis) by Top 10 Second Diagnoses, 2006**

| Additional Disease                       | ICD-10 AM Code | Number | %   |
|--|----------------|--------|-----|
| Heart Failure                            | I50            | 929    | 9.5 |
| Respiratory Failure                      | I96            | 883    | 9.1 |
| Pneumonia                                | J12-J18        | 857    | 8.8 |
| Diabetes Mellitus                        | E10-E14        | 503    | 5.2 |
| Atrial fibrillation                      | I48            | 461    | 4.7 |
| Hypertension                             | I10-I15        | 442    | 4.5 |
| Ischaemic Heart Disease                  | I20-I25        | 363    | 3.7 |
| Metabolic Disorders                      | E70-E89        | 312    | 3.2 |
| Other COPD                               | J40-J44, J47   | 255    | 2.6 |
| Other Acute Lower Respiratory Infections | J20-J22        | 236    | 2.4 |

In 2006, 3,154 (29%) COPD inpatient cases were repeat episodes of care in the same hospital.

COPD cases are not the most complex or costly of cases. Although they are 39% more expensive than the national average case, their substantial cost relates to the actual numbers involved. This point in many ways supports the view that many of these patients could be managed outside of the acute setting if adequate services and supports were available. There is a view that in the presence of such supports and services, the main criteria for inpatient acute hospitalisation is a requirement for ventilation. Only 698 (6.5%) of the 10,712 inpatient discharges with COPD as a principal diagnosis in 2006 required ventilation. Just over 9% had respiratory failure recorded as second diagnosis (Table 3.7).

### 3.4 Costs

Based on the INHALE report, the cost of respiratory disease<sup>7</sup> in 2006 was estimated to be in excess of €824 million, of which the cost to the health service was at least €437 million.<sup>(30)</sup> These are summarised in Table 3.9 below. For additional details, readers are referred to the INHALE report.<sup>(30)</sup> As evident from factors such as those mentioned in Table 3.10, these cost were an under-estimate of the actual cost in 2006. Therefore they are an even greater under-estimate of the current costs in 2008.

**Table 3.9 Estimated cost of respiratory disease 2006**

| Sector                    | Item                     | Cost 2006     |
|---------------------------|--------------------------|---------------|
| <b>Health Service</b>     |                          | <b>€437m</b>  |
| Primary Care (GMS)        |                          | €71m          |
|                           | GP Consultations         | - €56,699,240 |
|                           | Vaccinations             | -€12.9        |
|                           | Emergency nebulisers     | - €2.1m       |
| Medication                |                          | €106          |
|                           | General Medical Services | - €71.96m     |
|                           | Drug Payment Scheme      | - €30.45m     |
|                           | Long Term Illness        | - €0.36m      |
|                           | High Tech Drugs          | - €3.3m       |
| Hospital Costs (public)   |                          | €260.1m       |
|                           | inpatient care           | - €246m       |
|                           | day care                 | - €3.9m       |
|                           | OPD                      | - €10.2m      |
| Private health care costs |                          | €122.3m       |
|                           | GP Consultations         | - €18m        |

<sup>7</sup> Except where otherwise indicated, the term 'respiratory disease' refers to all diseases of the respiratory system and includes lung cancer

|                         |                |                  |
|-------------------------|----------------|------------------|
|                         | Medication     | - €47m           |
|                         | Inpatient care | - €57.3m         |
| <b>Society, Economy</b> |                | <b>€387.1 m.</b> |
|                         | Mortality      | - €187.1 m       |
|                         | Morbidity      | - €200m          |
| <b>TOTAL</b>            |                | <b>€824m</b>     |

Source: INHALE (30)

**Table 3.10 Reasons for underestimation of the true cost of respiratory disease**

| Sector                    | Comment  |
|---------------------------|--|
| Local Health Offices      | Excludes cost of supplying nebulisers for those eligible: estimated in 2006 to be in excess of €0.5m   |
|                           | Excludes cost of LTOT* for those eligible: estimated in 2006 to be in excess of €4m  |
| Medication                | Excludes antibiotics, steroids, Anti TB drugs, lung cancer drugs etc   |
|                           | Excludes cost of NRT** which for GMS patients was €5m (2004)   |
| Hospital Costs (public)   | See text for discussion  |
| Private health care costs | Excludes drug payment threshold for persons relying on the DPS***, costs for vaccination, nebulisers, oxygen and cost to access community allied health professionals.   |
| Society, Economy          | Mortality: The Human Capital Method gave the value of €187.1m but the Value of Statistical Life approach gave a cost of €1246m (30)  |
|                           | Excludes numbers on Long-term Invalidity Pensions due to respiratory disease, costs due to long-term absenteeism due to respiratory disease in workers or to work lost by carers of people with long-term chronic respiratory disease. |

\*Long term oxygen therapy

\*\*Nicotine replacement therapy

\*\*\*Drug Payment Scheme

As mentioned in the opening paragraph the 2006 costs are an under-estimate of the 2008 costs. Based on 2006 inpatient activity, the cost for inpatients with a principal diagnosis of respiratory disease has increased from €246m to €305 in 2008 and that for day cases from €3.9m to €5.6m, i.e. an increase of approximately 25%.(30). For those aged 35 years and over, 30% is accounted for by COPD at €70 million (Table 3.11) and a further 40% (€85m) due to respiratory infection, where COPD is a common underlying cause. The average COPD case cost, at €6,494 in 2008, is 39% higher than the national average case cost of €4,677.

**Table 3.11 Numbers of Inpatient Discharges and Bed Days Used (BDU), Mean Lengths of Stay (LOS) in Days (2006) and Estimated Casemix Costs (2008) by Respiratory Diagnosis for Ages 35+**

| Principal Diagnosis                            | Discharges N  | BDU            | Mean LOS    | Estimated Costs (€) |              |
|--|---------------|----------------|-------------|---------------------|--------------|
|  |               |                |             | Total               | Average      |
| Cancer of the Trachea, Bronchus & Lung         | 3,273         | 43,080         | 13.2        | 27,957,205          | 8,542        |
| Acute Upper Respiratory Infections & Influenza | 953           | 3,794          | 4.0         | 2,129,669           | 2,235        |
| Acute Lower Respiratory Infections             | 13,199        | 144,729        | 11.0        | 83,246,561          | 6,307        |
| COPD   | 10,712        | 111,217        | 10.4        | 69,562,624          | 6,494        |
| Asthma   | 1,248         | 7,076          | 5.7         | 4,782,869           | 3,832        |
| Other Respiratory Diseases                     | 6,114         | 65,861         | 10.8        | 46,474,553          | 7,601        |
| <b>Total</b>                                   | <b>35,499</b> | <b>375,757</b> | <b>10.6</b> | <b>234,153,482</b>  | <b>6,596</b> |

Sources: HIPE & NPRS Unit, ESRI and Casemix Unit, HSE.

### 3.5 Conclusion

This chapter confirms Ireland's major health burden due to respiratory diseases, especially COPD. Respiratory ill health is the third most frequently reported illness in adults. Ireland's respiratory health status compares poorly with our European neighbours. The downward mortality trends seen with CHD have not been seen for respiratory disease, although the major lifestyle risk factor, smoking, for both COPD and lung cancer is well recognised. There are worrying upward trends in female respiratory mortality and in socio-economic disparities.

Respiratory consultations account for 14.5% of GP consultations among those with GMS eligibility. COPD accounts for at least one third of hospital respiratory activity, both in terms of hospitalisations and bed days used. Ninety-one percent of COPD in-patient cases have co-morbidities. Only 6.2% of inpatient discharges with COPD as a principal diagnosis required ventilation. In 2006, 29% of COPD inpatient cases were repeat episodes of care in the same hospital.

Despite the limitations of data, there is sufficient information to indicate that a large amount of COPD is being dealt with at community level. However, hospital utilisation data – admissions via Emergency Departments, bed days usage, ventilation needs and both single and repeat episodes of care – suggest that at least some people admitted in 2006 may have been suitable for care in the community if services and supports were available.

Even with large gaps in epidemiologic data and costing systems, financial data confirms the large health service and personal health costs for individuals and the enormous economic impact of respiratory disease in Ireland.

## Chapter 4: Risk Factors

### Key Points

- Risk factor identification is important both for prevention and treatment of COPD.
- All risks for COPD results from host-environment interaction.
- Cigarette smoking is the most important risk factor – it is a factor in 85% of those with COPD.
- COPD prevalence is increasing among women, as their smoking rates increase.
- Lack of awareness is a risk factor for COPD in terms of delayed diagnosis and delayed intervention to slow progress.
- The genetic risk factor, alpha-1 anti-trypsin deficiency, affects 1-3% of those with COPD.
- COPD prevalence, morbidity and mortality increases with age as does the role of co-morbidities.
- COPD is inversely associated with socio-economic status. The effects are reflected in risk factors for COPD, the prevalence of COPD and the outcome for COPD in terms of morbidity and mortality.
- Urban air pollution causes 1% of COPD in countries such as Ireland. It also plays a role in the exacerbation of COPD in those with the disease.
- Occupational exposures can cause COPD independently of cigarette smoking but also increase the risk of the disease in the presence of those exposed to smoke.
- Current understanding of risk factors for COPD, while incomplete, is sufficient for action to be taken. In particular the tobacco epidemic requires the implementation of proven policies.

### 4.1 Introduction

The identification and management of risk factors is central to preventing and managing any disease.<sup>(15)</sup> A serious, but often unrecognised, risk factor for COPD is its poor general awareness among health professionals and the public. Respiratory health, in general, and COPD in particular has very little “currency” in the collective mind of the public.<sup>(51)</sup> Media coverage of respiratory health is comparatively low compared with that of cancer, Alzheimer’s disease or HIV/AIDS.<sup>(52)</sup> A study conducted by the British Thoracic Society in 2001 found that only one-in-three people had heard of COPD.<sup>(53)</sup> Furthermore, people with COPD often delay seeking medical help; one such study found that in 23% of patients with COPD the delay was up to ten years after symptoms developed.<sup>(54)</sup>

Low levels of awareness can impact negatively on diagnosis, care and treatment. As a result the management of COPD is often not prioritised from an investment or strategic

perspective.(55) A British Thoracic Society survey of GPs in 2002 reported that only 52% of GPs felt confident in diagnosing COPD.(56) It has also been found that 30% of patients with COPD were initially told they had asthma, 16% were told they had bronchitis and 10% were told they had emphysema. In addition less than half of those with COPD understood the link with smoking.(54)

## 4.2 Risk Factors

Risk factors for COPD result from a host-environment interaction (Table 4.1). Tobacco smoking is the single major risk factor for COPD. Therefore smoking prevention and smoking cessation are the most important interventions to reduce the burden of illness from COPD. Other risks include occupational hazards, air pollution and genetic factors.(57). It is imperative to focus on prevention and early intervention so as to reduce the numbers in Ireland living with severe respiratory disability.

**Table 4.1 Risk Factors for COPD(10, 15, 58, 59)**

| Host Factors  | Environmental Factors   |
|---|---|
| Genes (C)<br>Gender (A)<br>Age (A)<br>Growth and development of the lung (A)<br>Oxidative stress<br>Respiratory airway hypersensitivity (A)<br>Co-morbidities (A) | Inhalational particles<br>Outdoor air pollution (C if heavy)<br>Indoor air pollution (C if heavy)<br>Occupational exposures (C if heavy)<br>Tobacco smoke (C)<br>Social and economic level* (A)<br>Respiratory Infections (A) |

(A) additive, (C) causal adapted from(10)

\*Social and economic factors: are proxies for nutritional status, crowding, exposure to pollutants including work exposures and smoking exposure, access to health care and early respiratory infections)

The natural history of COPD is variable. Not all people follow the same course.(10),(60) Previously it was thought that 15-20% of smokers develop COPD. Now it is realised that it may be as high as 50%. (61-63) Genetic and other factors modify an individual's risk.(64) It is not understood why some smokers develop COPD while others do not. Of two people with the same smoking history, only one may develop COPD due to differences in genetic predisposition to the disease or some other factor(s). Risk factors for COPD may also be related in more complex ways, e.g. gender may influence whether a person takes up smoking or experiences certain occupational or environmental exposures.

As non-smokers can develop chronic airflow obstruction, more research focused on this group is necessary to improve understanding of COPD(29, 65-67) and to improve the understanding of the relationships and interactions among other risk factors.(68).

## 4.2 Host Factors

### 4.2.1 Genes

COPD is an example of gene-environment interaction.(15) Abnormalities in many genes may affect a person's risk of developing COPD.(17) Exploratory studies have revealed a number of genes that influence a person's risk of COPD(69) and many of these genes are thought to be involved in inflammation.(70) Parental lung function is related to lung function in children.(71) A significant familial risk of airflow obstruction has been observed in smoking siblings of patients with severe COPD, suggesting that genetic factors could influence this susceptibility.(72)

The best documented and only proven genetic risk factor for COPD is a hereditary deficiency of alpha-1 antitrypsin (AAT).(73) It illustrates the interaction between genes and environmental exposures leading to COPD and provides a model for how other genetic risk factors are thought to contribute to COPD.(15) This recessive trait is most commonly seen in individuals of Northern European origin.(74) The incidence of AAT deficiency in the general Caucasian population is estimated to be between 1/2,500 and 1/3,000 in the US.(75) It arises in 1-3% of patients with COPD.(73) Smoking greatly increases the risk of those with the deficiency developing the disease. More detail of AAT deficiency may be found in the appendix 2.

Currently targeted AAT screening is aimed at those with COPD or poorly controlled asthma, first degree relatives of those with AAT deficiency and patients with cryptogenic liver disease.(76)

#### **4.2.2 Gender**

Historically COPD has been more common in men than in women. This is related to patterns of smoking and occupational exposures.(77, 78) Some studies suggest that women are more susceptible to the effects of tobacco smoke and the development of COPD than men.(11, 29, 77, 79, 80) COPD will increase in Irish women in line with their increased smoking rates.

#### **4.2.3 Age**

COPD prevalence, morbidity and mortality increase with age. International studies report a prevalence ranging from 18% - 32% in those aged  $\geq 60$  years.(20)

Lung function reaches its peak in young adults and starts to decline in the third and fourth decades of life.(81) The natural rate of decline of lung function (Forced Expiratory Volume or FEV1) after 25 years of age is 15-30 mL per year. In 'susceptible' smokers who continue to smoke, the decline averages 60 mL per year and may be as great as 150 - 200 mL per year in some individuals.(11, 12)

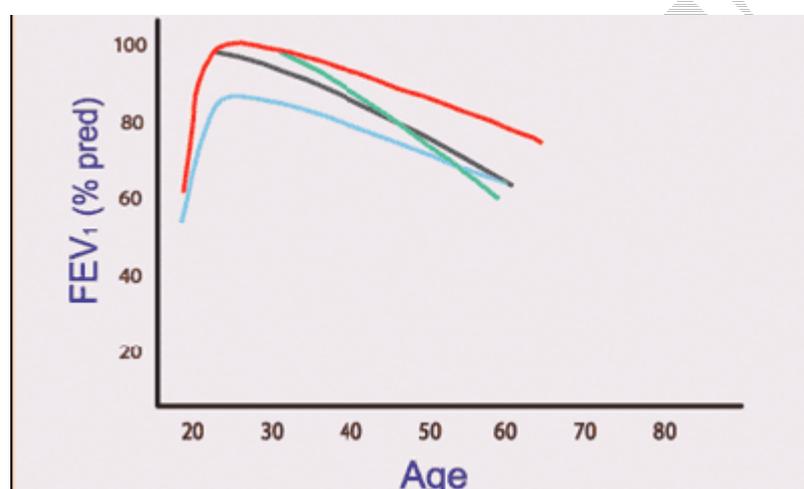
#### **4.2.4 Respiratory airway hyper-sensitivity and asthma**

Airway hyper-responsiveness is a risk factor for COPD.(14) An overlap of up to 30% between people with COPD and asthma has been reported.(13) In one study, adults with asthma had a twelve-fold higher risk of acquiring COPD over time than those without asthma, having adjusted for smoking.(82) In another study 20% of people with asthma developed COPD.(83)

#### 4.2.5 Growth and lung development

Accelerated decline in lung function is the single most important feature in COPD. Any factor affecting lung growth during gestation, birth and early childhood potentially increases an individual's risk of developing COPD(84-86) by lowering the maximally attained lung function in early adulthood.(28) This reduced growth will, if combined with a shortened plateau phase in smokers, increase the risk of COPD as shown in Figure 4.1.(87)

**Figure 4.1 Age effects on pulmonary function (87)**



The normal course of forced expiratory volume in one second (FEV<sub>1</sub>) over time (—) is compared with the result of impaired growth of lung function (—), an accelerated decline (—) and a shortened plateau phase (—). All three abnormalities can be combined.

#### 4.2.6 Oxidative stress

The lungs are continuously exposed to oxidants generated from air pollutants or cigarette smoke. Lung cells are generally protected against this oxidative challenge. When the balance tilts in favour of the oxidants, oxidative stress occurs which in turn plays a role in the pathogenesis of COPD.(88)

#### 4.2.7 Co-morbidities

Risk factors such as smoking are common to many of the leading causes of death and of chronic disease. Risk factors interact, often in a multiplicative fashion. Risk factors cluster in individuals as do chronic diseases such as COPD.

Smoking, the major risk factor for COPD, can lead to other concurrent morbidities such as cardio-vascular disease, cancer, diabetes mellitus, dementia and degenerative joint disease.

In addition to these concurrent co-morbidities, are COPD's complicating co-morbidities which include mental health effects, cor pulmonale, polycythaemia, osteoporosis, myopathies and other respiratory effects.(89, 90) Table 4.2 shows the various co-morbidities in terms of body systems.

**Table 4.2 Main COPD co-morbidities(57)**

|  |
|--|
| <p><b>Respiratory:</b> Respiratory failure, asthma, allergy, pneumonia, pulmonary embolism, pulmonary vascular disease, respiratory infections, rhinitis</p> <p><b>Cardio-vascular:</b> Ischaemic heart disease, hypertension, congestive heart failure, VT/VF/cardiac arrest, atrial fibrillation, other arrhythmias, angina, myocardial infarction, stroke, peripheral atherosclerosis</p> <p><b>Malignant:</b> Lung cancer, thoracic malignancy, malignancies</p> <p><b>Endocrine:</b> obesity, diabetes, hyperlipidaemia, nutritional depletion</p> <p><b>Gastro-intestinal:</b> Digestive ulcer, gastro-oesophageal reflux symptoms, faecal incontinence (females&gt;40 yrs of age), <i>Candida oesophagitis</i> in elderly patients</p> <p><b>Renal Disease</b></p> <p><b>Osteo-articular:</b> bone fractures, articular disorders, arthritis, osteoporosis, osteopenia</p> <p><b>Ocular:</b> cataracts, glaucoma</p> <p><b>Psychiatric:</b> depression/anxiety</p> <p><b>Others:</b> Skin diseases, migraine, poor health-related quality of life</p> |
|--|

VT: ventricular tachycardia, VF: ventricular fibrillation

### 4.3 Environmental Factors

#### 4.3.1 Inhalational exposures

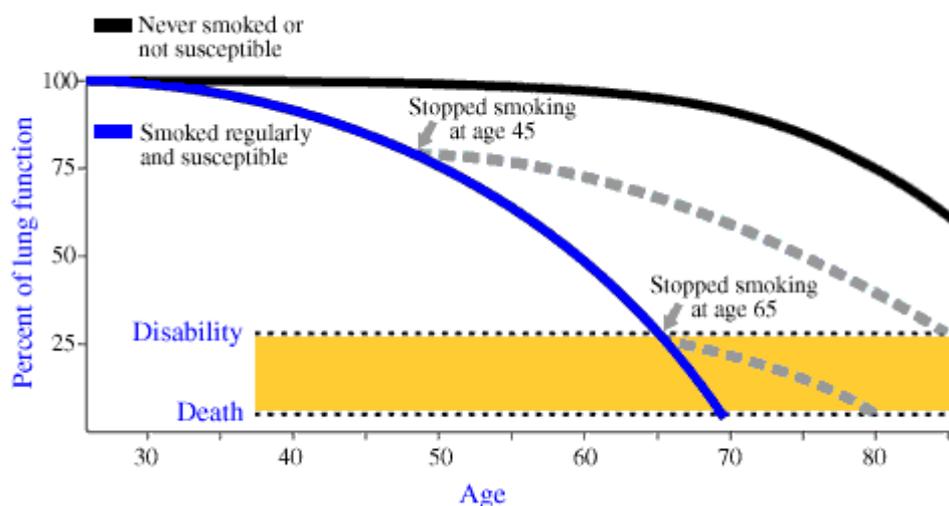
Over their lifetime, individuals are exposed to a variety of different types of inhaled particles. Each type of particle contributes a different weight to the risk of COPD.(15)

##### a) Tobacco

Tobacco is a global agent of death. Tobacco is the only legal consumer product that can harm everyone exposed to it. It kills up to half of those who use it as intended. The global tobacco epidemic threatens more lives than any infectious disease. The solution requires the implementation of proven public policies.(91)

COPD is a progressive disease. An accelerated decline in lung function is the single most important feature of COPD and smoking is the commonest risk factor for such a decline. If exposure is stopped, the disease may still progress, mainly due to the decline in lung function that normally occurs with ageing but the rate of decline is less than in those who continue to smoke. This is illustrated by Figure 4.2.

Figure 4.2 Time course of COPD(adapted from Fletcher C and Peto R).(12).



In view of the extent of damage to health and the particular relationship with COPD, tobacco as a risk factor will be discussed under a number of headings.

The effects of tobacco on COPD:

- Worldwide, cigarette smoking is by far the commonest risk factor for COPD.(15) It is a factor for 85% of those with COPD.(92) Cigarette smokers have a greater annual rate of decline in lung function than non-smokers.(93)
- As many as 50% of smokers may develop COPD(61-63) as opposed to the 15-20% which was previously thought to be the case.
- Pipe and cigar smokers have greater COPD morbidity and mortality rates than non-smokers, although their rates are lower than those for cigarette smokers.(93)
- Most of tobacco's damage to health does not become evident until years or even decades after the onset of use.(91) Most people with COPD have smoked over 20 pack years (20 per day for 20 years),(10) i.e. the risk for COPD in smokers is dose-related.(92)
- In 2002, tobacco was the leading contributor to the burden of disease in Ireland: it accounted for 11.8% of disability adjusted life years (DALYs).(94) In the WHO European region, smoking accounted for 12.3% of total years of life lost from premature mortality and years lived in disability (DALYS).(94)
- In high-income countries, WHO estimates that 73% of COPD mortality is related to smoking.(2) In the UK, 87% of deaths in men with COPD are due to smoking while for women the figure is 84%.(95)

#### Smoking Prevalence

The 2007 Slán Survey found that 29% of Irish adults are current smokers (31% males, 27% females). (6) Among those aged 18-29 years the smoking rate was 35%, while among the

lower social class groups (5,6) the figure was 37%. Among homeless men in Dublin aged 40-45 years, 78% smoke (7) while among Dublin bus drivers, the prevalence for current smoking is 44%.(96) Smokers are most common among members of lone parent households (53.9%), the unemployed (48.6%) and the ill or disabled (37.6%).(97)

Smokers have an average income of €17,937 which is almost €3,000 less than their non smoking counterparts.(97) The “at risk of poverty rate” for smokers at 21.4% compares to 16.1% for non smokers.(97). Smokers are over 2.5 times more likely to be in consistent poverty than non smokers (10.9% vs 4.2 %).(97)

These wide social class differences within smoking prevalence figures reflect those of COPD morbidity and mortality figures. The growing concentration of smoking in the lower social classes observed throughout the WHO European Region will lead to a widening gap in current and future health outcomes and is of concern throughout Western European countries.(98)

#### Passive/Second Hand Smoking

Passive exposure to cigarette smoke (environmental tobacco smoke (ETS)) contributes to COPD.(99-102) Individuals who are highly exposed to passive smoking (more than 40hours/week for over 5 years) are 48% more likely to present with COPD than are unexposed individuals.(19, 20)

The figures for smoking in pregnancy in Ireland are between 20-33% of women (personal communication C. Hayes). However, in at least one maternity hospital, the figure may be as high as 50%. Smoking during pregnancy poses a risk for the foetus, by affecting lung growth and development in utero and possibly the priming of the immune system.(103, 104)

#### **b) Outdoor pollution**

WHO estimates that urban air pollution causes 1% of COPD cases in high-income countries such as Ireland.(2) Air pollution is also linked to lower respiratory infections and acute cardiopulmonary events, which are important in both the development and progression of COPD.(68)

Both coal burning and traffic emissions are major sources of particulate exposure worldwide (105) and in cities are associated with reduction of respiratory function. (106) In terms of black smoke, Hoek et al in the Netherlands reported for adults aged 55-69 years a relative risk (RR) of death of 1.34 (95% CI: 0.68-2.64) with background black smoke levels of 10microg/m<sup>3</sup>.(107) Living within 100m of a highway or 50m of a major road was associated with a RR of 1.95 (95% CI: 1.09-3.51). The relative risk with 10microg/m<sup>3</sup> black smoke almost doubled (1.71 95% CI: 0.68-2.64) when local sources of black smoke were included in the

model in addition to background levels. It would appear that using only community averaged background concentrations of pollutants under-estimates the health burden attributable to elevated concentrations in the vicinity of sources of black smoke.

Following the ban on burning of bituminous coal in Dublin in 1990, there was a two thirds reduction in black smoke concentration together with a decline in all-causes of deaths, in particular respiratory deaths.(108) After the ban, the average black smoke concentration declined in Dublin by 35.6microg/m<sup>3</sup> (70% reduction) while the adjusted respiratory deaths reduced by 15.5% i.e. there were approximately 116 fewer respiratory deaths in Dublin the year after the ban.(16)

The effects of long-term exposure to single pollutants as part of atmospheric pollution and the relative effects of short-term, high-peak exposures and long-term, low-level exposures are difficult to assess and still unknown in terms of COPD.(15)

#### **c) Indoor air pollutants**

The most important risk factor globally for development of COPD may be exposure to biomass fuels used to heat and cook by almost three billion people.(68) (15) In countries of low and middle income, 35% of people with COPD develop the disorder after exposure to indoor smoke from biomass fuels.(2)

#### **d) Occupational dust, vapours and fumes**

Occupational dust, chemicals and vapours can both cause COPD independently of cigarette smoking and increase the risk of the disease in the presence of concurrent smoking.(17)

Although the risk from occupational exposures is smaller than with tobacco smoke, the contribution of occupational exposures to COPD is important as a large number of the population can be affected.(17) A US survey of almost 10,000 adults aged 30-75 years estimated the fraction of COPD attributable to work was 19.2% overall and 31.1% among 'never smokers'.(18) The American Thoracic Society estimates that occupational exposures account for 10-20% of symptoms consistent with COPD.(109) Following the smoke free legislation of 2004 in Ireland, ambient air nicotine concentrations decreased by 83% and bar workers' exposure to second hand smoke fell from 30 hours per week to zero.(110)

#### **4.3.2 Socio-economic and related factors**

The risk of developing COPD is inversely related to socio-economic status.(111) Low socioeconomic status is a surrogate measure for many factors, including nutritional status, crowding, exposure to pollutants including work exposures and smoking exposure, access to health care and early respiratory infections, all of which increase the risk of COPD. (112-116)

In Ireland, fuel poverty (the inability to heat the home to a safe and comfortable temperature owing to low income and poor household energy efficiency) is amongst the highest in the EU.(117) One in five fuel poor households in Ireland report a member with a long standing illness. The mean internal temperature (15 degrees Celsius) of Irish homes is a temperature at which there is increased risk of respiratory infection. (118, Collins, 1986 #272)

In a study of excess winter mortality in Ireland and housing standards, Clinch et al reported that the Irish seasonal variation in excess mortality at 15% is amongst the highest in Europe, with cardio-vascular and respiratory disease accounting for 85% of the estimated 1,467 mean excess winter deaths.(118-120) This may result from the poor thermal standard of Irish housing.(118)

For a 10 year period (1986-1995), 271 (6.2%) of the yearly total of 4,380 respiratory deaths were associated with poor housing standards. This represents 18.5% of the 1,467 excess seasonal deaths overall and represents 57% of excess winter mortality from respiratory disease.(118-120) The same study, showed that in Ireland 69% of excess winter mortality from respiratory disease (165 deaths) arose in the poorest three (of 11) socio-economic groups (SEGs).(5) In relative terms, there is a 5% difference between the incidence of excess winter respiratory deaths in the poorest and richest SEG. Of the excess winter deaths caused by respiratory disease, 90% occur among those aged over 65 years.

In an update on the above paper, for the years 1988-1997, the excess winter mortality as a percentage was 21%, a deterioration on the 1986-1995 picture.(121)

**Nutrition:** The role of nutrition as an independent risk factor, as opposed to a socio-economic effect, for the development of COPD is unclear.(15). However, malnutrition and weight loss can reduce respiratory muscle strength and lung CT scans of women chronically malnourished from anorexia nervosa show emphysema-like changes.(122, 123)

#### **4.3.3 Respiratory Infections**

Severe childhood respiratory infections are associated both with reduced lung function and increased respiratory symptoms in adulthood and in adults contribute to both the pathogenesis and progression of COPD.(84, 124, 125, Retamales, 2001 #258, 126)

#### **4.4 Conclusion**

COPD will increase globally in the coming decades due to increasing population, changing age distribution, increasing life expectancy and the ongoing uptake of cigarette smoking especially among women.(69, 127-129) This increase is preventable. However, prevention requires both awareness and the implementation of healthy public policies.

The link with smoking has been known for decades. The future rise of COPD among women is predictable. The association between COPD and socio-economic factors relates not just to an individual's lifestyle but also to socio-economic public policies such as housing standards, air pollution, and service provision.

The current prevalence of smoking in Ireland, whether taking the national figure of 29% or looking at the even higher levels across various sub-groups, indicate that Ireland's epidemic of smoking related diseases will increase. Exposure to passive smoking may have fallen for those in the hospitality industry but for the foetus, toddler and child, their exposure continues as does the likelihood that they too will become current smokers in their teenage years. Given the devastation to health caused by smoking, effective public policies combined with quit smoking supports at individual level are the most effective measures which can be taken to improve the health of Irish population. It should be the public health priority.

COPD is preventable. Its course for many is predictable. Its progress can be slowed. Quality and quantity of life can be improved. This requires commitment from policy makers, awareness among the public and professionals, leading to early diagnosis, and implementation of effective interventions including at population level, policies on smoking, on socio-economic factors and on air pollution including occupational exposures and at individual level, services to support smoking cessation, to test for AAT deficiency and to provide treatment.

## Chapter 5 Current Services

### Key Points

- An interdisciplinary approach from a variety of health professionals is required to address the complex problems posed by people with COPD.
- Management of patients with COPD involves self-care, primary care, acute hospital care and rehabilitation.
- Currently for many patients with COPD, care is fragmented across settings and disciplines with inconsistencies in access to essential services in both community and hospital settings.
- The majority of patients with COPD could be managed in primary care, especially if diagnosed early. Quality spirometry, the key to diagnosis of COPD, is not currently available for all patients who need it.
- Smoking cessation is the single most effective way both to reduce risk of COPD and slow its progression. There are serious gaps in access to smoking cessation services both within and between health care settings especially the acute hospital setting.
- Patient education, appropriate self-management and support are essential elements of COPD management. Currently these are patchy and variable.
- Pulmonary Rehabilitation Programmes should be available to patients at the time of diagnosis and as required thereafter. Availability and access to these are currently a major gap. Current supply is such that most patients cannot access this essential service.
- NCPE data suggests prescribing generally is along best practice guidelines and in line with increasing disease severity. However, NCPE data raises questions about some prescribing variations and potential adverse drug reactions.
- There are wide variations in numbers of nebulisers issued by LHOs based on data reported. Maintenance arrangements and infection control policies for nebulisers so issued also show wide variations.
- Key to managing patients in the primary care setting is rapid access to supports and respiratory expertise when required. For the majority of GPs and their patients with COPD such access is not available and ED attendance/acute hospital admission may be the only option.
- Commencement on long term home oxygen is a major event in a patient's life and it is costly to the health service. There appears to be wide variation between LHOs in terms of numbers on home oxygen and procedures governing prescribing and monitoring of same.

- NIV is not available in all settings which accept patients with exacerbations of COPD and potential Type 2 respiratory failure.
- Staffing levels, both general and specialist respiratory, currently working within and across locations are patchy across the country, settings and locations.

## **5.1 Introduction**

The aim of COPD services is to provide evidence-based prevention, treatment and care. Chronic disease management is complex. It includes self-care, primary care, acute hospital care, rehabilitation and palliative care. The problems posed by COPD, especially in people with co-morbidities, require a variety of health professional competencies and a multidisciplinary approach. Currently for many patients with COPD, care is fragmented across many settings and disciplines.

### **5.1.1 Approach to care**

While prevention of COPD is the ultimate goal, once the disease develops the goals of effective management are to:

- Improve health status
- Prevent disease progression
- Improve exercise tolerance
- Relieve symptoms
- Prevent and treat complications
- Prevent and treat exacerbations
- Prevent or minimise side effects of treatment
- Reduce mortality.

In this chapter the GOLD guidelines for COPD (see Chapter 7) were used as a framework to describe current services and to highlight service gaps. The GOLD approach examines the need for integration of care under four main components:

Component 1: Assess and Monitor Disease

Component 2: Reduce Risk Factors

Component 3: Manage Stable COPD

Component 4: Manage Exacerbations.

The key to all of the above is human resources.

There is overlap between the different components, e.g. prevention is relevant to all sections.

### **5.1.2 Surveys**

A number of national surveys were undertaken to describe COPD services full details of which are available in the accompanying technical reports. These were:

- Surveys of services provided by four health professional groups:
  - Physiotherapists services
  - Respiratory Nurse Specialist services
  - Respiratory Scientist services
  - General Practitioners services.
  
- Surveys of services in two settings:
  - Community services
  - Acute hospitals.

Research was also conducted by the National Centre for Pharmaco-economics (NCPE) on prescribing for COPD.

Other professional groups provide care to patients with COPD, e.g. speech and language therapists, occupational therapists, social workers, clinical nutritionists and palliative care specialists. Their views were obtained as part of the consultation exercise but were not sought in specific surveys.

An outline of the aims of the six surveys and the response rates is provided below:

**a) Community services**

- Describe home oxygen and nebuliser utilisation and access to non-acute hospital beds.
- All Local Health Areas (32) were surveyed via their Local Health Offices (LHOs). The response rate was 44% (14 Local Health Areas). This covered a population of 1,792,818.

**b) Acute hospital resources**

- Describe the services available to people with COPD in acute HSE hospitals
- Thirty-six acute public hospitals with Emergency Departments (ED) were surveyed. The response rate was 72% (26 hospitals).

**c) COPD physiotherapy services**

- Document current physiotherapy service provision and identify gaps.
- One hundred sites were surveyed. The response rate was 57% and included acute hospitals, community services and long term care facilities.

**e) Respiratory nurse specialist care**

- Outline available Respiratory Nurse Specialist services
- All members of ANAIL (35) were surveyed of whom 21(60%) responded.

**f) Respiratory scientists**

- Identify respiratory laboratory staffing, workload, referral procedures and involvement of staff in patient education
- Ten (27%) of the 37 locations surveyed responded.

**g) General Practitioner (GP) survey**

- Describe the range of services available to patients in the Primary Care setting and document the gaps in services

- Obtain the views of GPs on service improvements
- Five hundred (500) GPs were randomly selected and surveyed by post with the assistance of the ICGP. The response rate was 24.2%.

All surveys were national. Responses came from all geographic / network areas. It is likely that respondents were those with the most interest in COPD. The results of the surveys are presented in percentages rather than numbers despite the small numbers in some cases. Key findings from the surveys are described as they relate to the four components of the GOLD approach.

## **5.2 Component 1: Assess and Monitor Disease**

Early diagnosis is the key to good disease management. Lack of COPD awareness and the stigma often associated with this smoking related disease can delay diagnosis. Chronic cough and /or dyspnoea are not normal although some people may consider these part of everyday life. The term COPD is not well understood by patients, the general public or by some health professionals. Many people continue to use terms like 'bronchitis' or 'asthma' (long after their airway obstruction has become irreversible). Research from Canada shows for example (130):

- Only 46% of Canadians have heard of chronic obstructive pulmonary disease and 13% understand the acronym COPD, even though COPD is their fourth leading cause of death.
- Only 26% of doctors in Canada consider themselves to be very familiar with Canadian Thoracic Society's COPD guidelines.

Although a national study has not been done in Ireland, it is likely that the situation is the same. As part of the consultation exercise, patients and GPs stated that they often use the terms asthma or bronchitis in preference to COPD. Low levels of awareness translate into under-diagnosis and poor service development.

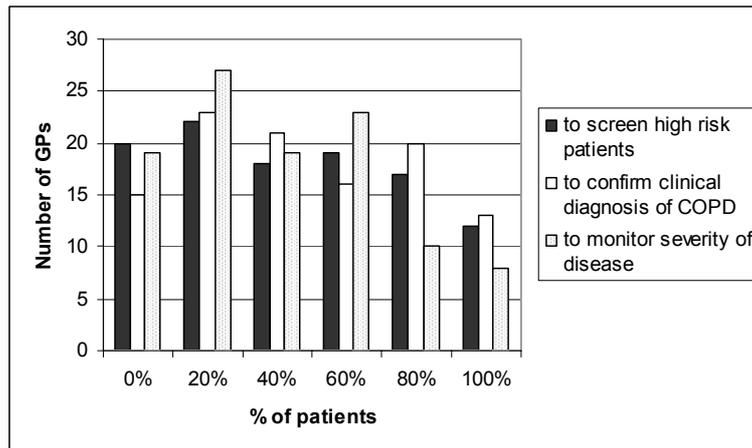
### **5.2.1 Diagnostic Services**

Accurate diagnosis requires quality spirometry.<sup>8</sup> Figure 5.1 shows the use of spirometry in general practice. 53.7% of GPs had access to spirometry in their own practice. They generally used spirometry to confirm diagnosis, to monitor disease severity and less frequently to screen people at high risk.

#### **Figure 5.1 Use of Spirometry in General Practice**

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<sup>8</sup> Spirometry: a breathing test used to diagnose COPD and to monitor any changes in lung function over time.



Of GP practices that had access to spirometry, this test was conducted by either the practice nurse (64%) or GP (27%). Their training in performing spirometry was: none (9%), local hospital (6%), industry/supplier provided (9%), demonstrations (22%), self taught/experience (22%) and formal course (31%).

Results were interpreted by the GP (83%) and practice nurse (15%). Their training in interpretation was: none (21%), industry/supplier provided (17%), formal course (21%) and self taught/ college/special training (42%).

18% had arrangements for an annual service, while 11% had other definite arrangements for calibration and maintenance of their spirometer. Almost half (48.9%) had no arrangements in place and 13% did not know of their practice arrangement.

Additional pulmonary function tests (PFTs) can provide useful information in some patients. In relation to GPs accessing full PFTs:

- 59% found this service difficult or impossible to access
- 21% found access easy or very easy
- Waiting times to access PFTs for GP referrals ranged from 1 day to 6 months. For patients referred by hospitals, the waiting times ranged from 1 day to 6 weeks (see technical report). Many laboratories do not accept GP referrals.

Only 23% (6) of the acute hospitals surveyed employed respiratory scientists. Eight of the ten respiratory laboratories which responded accepted referrals from other acute hospitals. Table 5.1 shows the responses from these respiratory scientists regarding the tests they provide and accepted sources of referral. The data shows that the service is limited.

**Table 5.1 Respiratory Laboratories Tests & Sources of Referrals (N=10)**

| TEST | TEST NOT AVAILABLE VIA LAB | RESPIRATORY TEAM MEMBER | OTHER HOSPITAL CONSULT | ****MAU | ED | GPS |
|------|----------------------------|-------------------------|------------------------|---------|----|-----|
|      |                            |                         |                        |         |    |     |

|                                   |   |    | ANT |   |   |   |
|-----------------------------------|---|----|-----|---|---|---|
| Full PFTs*                        | - | 10 | 10  | 6 | 9 | 6 |
| Max Respiratory Pressures         | 2 | 8  | 8   | 2 | 5 | 3 |
| Skin Allergy                      | - | 10 | 7   | 3 | 5 | 4 |
| Bronchial Provocation             | - | 10 | -   | - | - | - |
| 6 min walk                        | 5 | 4  | 2   | - | - | - |
| Cardio-pulmonary exercise tests   | 1 | 9  | 3   | - | - | - |
| **LTOT assessment                 | 8 | 2  | 1   | - | - | - |
| Fitness to fly                    | 8 | 2  | -   | - | - | - |
| ***NIV                            | 6 | 4  | -   | - | - | - |
| Overnight oximetry (in-patients)  | 3 | 7  | 5   | 1 | 2 | 1 |
| Overnight oximetry (out-patients) | 5 | 5  | 1   | - | - | - |

\*Full PFTs: spirometry, diffusion capacity, lung volumes and bronchodilator response

\*\*LTOT: long term home oxygen

\*\*\*NIV: non invasive ventilation

\*\*\*\*MAU: medical assessment unit

### 5.2.2 Service Gaps / Deficits

Most people with COPD can be managed in primary care, especially if diagnosed early. Occasionally a small number of patients require expertise and monitoring by respiratory specialist services, in conjunction with their GP and Primary Care Team.

Essential to early diagnosis are awareness by the patient and health professional and easy access to quality diagnostic services, especially spirometry.

- Quality spirometry is as essential to diagnosis as smoking is to risk factor reduction. Currently spirometry is not readily available to all patients attending Primary Care and where it is available the quality of both the performance and interpretation of same are variable.
- Poor access to PFTs, either because these are not provided or restricted by virtue of referral source, works against a patient centred service and the provision of care in the most appropriate setting.

## 5.3 Component 2: Reduce Risk Factors to Prevent COPD

The burden of COPD can be reduced by minimising the impact of known risk factors. The main risk factor is smoking. While tobacco dependence is a chronic disease itself, it is never too late to quit. Flexible smoking cessation services need to be offered repeatedly to all patients who smoke.

### 5.3.1 Smoking

Smoking prevention and cessation is the single most effective way to reduce COPD risk and slow its progression. Quitting smoking at any stage can prevent or delay the development of airflow limitation and reduce its progression. Smoking cessation services should always be

part of COPD services. The *Five Step Programme* outlined in Chapter 7, recognises the addictive nature of tobacco dependence and that relapse is common.

Irish public policies protect people from tobacco smoke through taxation, legislated advertising bans, specified smoke-free areas, and written health warnings on tobacco products.(131) Other measures that could be introduced include pictorial warnings on tobacco products, voluntary smoke-free health service premises and smoke-free cars when children are passengers.

Smokers are offered help to stop smoking by the 'Toll Free Quitline', nicotine replacement therapy (NRT) available in pharmacies over the counter (with limited reimbursements), by Bupropion or similar drug (with limited reimbursements) available in pharmacies with prescription and smoking cessation programmes. Other initiatives include media and education campaigns (e.g. Social Political and Health Education) and developing health promoting institutions.

Smoking cessation services are provided nationally in various formats but there is no uniform approach to delivery. Services are provided in some primary care settings, some hospitals and other health care settings. To varying extents the following services are provided:

- One-to-one support for people who wish to stop
  - Group support in the form of a six week programmes
  - Awareness days
  - Smoking cessation training in Brief and Intensive interventions
  - Irish Heart Foundation and the Irish Cancer Society support cessation efforts and both run programmes and provide training in this area
  - A number of other initiatives are in place around the country which facilitate smoking cessation and discourage people from taking-up the habit.

From the primary care perspective, 81% of GPs reported that access to smoking cessation services for their patients was easy / very easy but 11.7% said it was difficult/impossible. Most GPs said that access to NRT products for their patients was easy. Information provided by the NCPE (see Technical Reports) reported that over 5,000 GMS patients aged over 35 years on treatment consistent with obstructive airways disease were prescribed NRT in 2006. This ranged from 4.6 to 9.7 per 100,000 GMS eligible population across former health board areas.

In the acute hospital setting, Smoking Cessation Officers (SCO) were available in 69%(18) sites surveyed. In a small number of cases these services were shared with the community sector. However, as can be seen from Table 5.2, even for those hospitals with the service, access for people with COPD was variable and unequal.

**Table 5.2 Access to Hospital Smoking Cessation Service for Patients with COPD**

| <b>Patients with COPD</b>                        | <b>Smoking Cessation Officer</b> |
|--|----------------------------------|
| All in-patients                                  | 65.4%                            |
| All out-patients                                 | 53.8%                            |
| A&E/ MAU   | 26.9%                            |
| Patients directly referred by GP                 | 15.4%                            |
| In-patients under care of respiratory team only  | 11.5%                            |
| Out-patients under care of respiratory team only | 7.7%                             |

### **5.3.2 Alpha One Anti Trypsin (AAT) deficiency detection**

Not all smokers develop COPD. As discussed in Chapter 4, gene-environment interaction is important. The most understood gene effect is AAT deficiency. Cigarette smoke is the single most important risk factor for Alpha 1 patients in the development of COPD.

Currently in Ireland, targeted AAT screening is aimed at those with COPD, poorly controlled asthma, first degree relatives of those with AAT deficiency and patients with cryptogenic liver disease.(76) Alpha 1 testing is available in a number of hospitals in eight counties (Appendix 2). Those tested to date are at the more severe end of the COPD spectrum (Appendix 2).

The Alpha One Foundation, in addition to targeted testing, raises awareness of the condition, identifies research needs and facilitates a patient support group. It runs the AAT deficiency registry which helps identify effective treatments, research and information needs.

### **5.3.3 Service Gaps / Deficits**

Smoking cessation is the single most effective way to reduce risk of COPD and slow its progression. Cessation services should always be offered to all people with smoking related illness including COPD. All front line clinical staff should have brief intervention smoking cessation skills as part of their core competencies. There are gaps in the availability of smoking cessation services especially it would appear in the acute hospital setting.

Many people who are diagnosed with AAT deficiency have advanced COPD. This suggests that there is either delayed diagnosis of COPD, lack awareness of the link with AAT deficiency or lack of awareness of the benefit of diagnosing AAT early, in terms of managing lung and liver complications and screening first degree relatives.

## **5.4 Component 3: Manage Stable COPD**

Once COPD has been diagnosed, the goal of treatment is to ensure effective patient care to slow disease progression (see Section 5.1.1). Many patients have a disease course which is relatively stable but as the disease progresses further deterioration in lung function and

quality of life will occur. The key in this component is to slow such progression. Access to services can dictate whether care occurs mainly via community or acute hospital services.

In patients with stable COPD the essentials of management include assessment of the individual's disease severity, taking account of their symptoms, airflow limitation, frequency and severity of exacerbations and the nature of complications, co-morbidities, and general health status.

Most patients with COPD are stable most of the time, albeit at different levels of severity. They can receive most of their care in the primary care setting. This component is the largest in terms of this overview of services.

#### **5.4.1 Non pharmacological management**

##### **a) Patient education, self management and support:**

Patient education, appropriate self-management and support are essential elements of disease management. Each of these are elements in their own right. Results of the surveys undertaken for this strategy found that:

- 42% of GPs found it easy / very easy to access education for their patients with COPD but 35% found this difficult / impossible
- 15% of respiratory nurse specialists provide outreach services for inpatients and for approximately 25% of out-patients
- In 47% of acute hospitals with physiotherapists, they demonstrated inhaler technique to inpatients and to 40% of out-patients.
- In 88% of acute hospitals with physiotherapists they provided home exercise programmes for inpatients and for 58% of out-patients. 85% of PCCC based physiotherapists provided this service.
- Over 70% of physiotherapists in acute hospitals were involved in ward based rehabilitation, instruction in airway clearance techniques, advice regarding the management of dyspnoea and the provision of adjuncts (e.g. NIV). Less than 60% of respondents offered these services to out-patients.
- In acute hospitals with respiratory nurse specialists, 84% of these nurses provided self-management plans for in-patients with COPD while 70% provided them in the out-patient setting.
- In 59% of acute hospitals, physiotherapists provided patient self-management programmes. 75% of PCCC based physiotherapists provided this service.

Patient support groups can play a key role in helping patients manage chronic diseases such as COPD. For 70% of GPs access to COPD patient support groups for their patients was reported as difficult/impossible. Apart from the support provided through the Alpha-One Foundation for those with AAT deficiency, there are only two COPD patient support groups in

the Ireland. How this compares with Northern Ireland is shown in Appendix 3. Pharmaceutical companies provide information days for patients with COPD on relevant topics.

### **b) Pulmonary Rehabilitation Programmes (PRP):**

Multi-disciplinary evidence-based Pulmonary Rehabilitation Programmes (PRP) should be available to patients at the time of diagnosis and as required thereafter (Chapter 7). There are gaps in relation to rehabilitation services:

#### **i) Access and availability:**

- The majority of people with COPD are diagnosed in Primary Care yet only 8% of GPs could access pulmonary rehabilitation services for their patients.
- Nearly 40% of acute hospitals confirmed that they had a formal PRP. However, this included one which was completing a pilot programme and one programme which only had a physiotherapy component (i.e. not multidisciplinary).
- In acute hospitals where there were respiratory nurse specialists, 45% of them were unable to access PRP for their patients.
- From the perspective of physiotherapists, 21% worked in hospitals with a PRP service. Of the sites with a PRP:
  - 66% of PRPs were co-ordinated by senior physiotherapists. The remainder were jointly co-ordinated by a senior physiotherapist and a clinical nurse specialist.
  - 33% did not have approved staffing.
  - 41% of sites did not have dedicated space.
  - Programme length varied from 6-12 weeks. Mean programme length was 8 weeks.
  - The mean throughput of patients was 40 patients per year at each site.

#### **ii) Referrals to PRP:**

Referrals for pulmonary rehabilitation programmes were usually only accepted from hospital based services. Only 20% accepted referrals from GPs (see acute hospital survey: Technical report).

#### **iii) Waiting Times:**

Waiting times for Pulmonary Rehabilitation Programmes, (apart from one location which had no waiting time), ranged from 2 months to 18 months. This is in the context that most did not accept referrals from GPs.

#### **iv) PRP Components:**

Evidence-based guidelines are clear about the required components of PRPs and their multi-disciplinary nature. While all the Irish PRPs indicated that they provided supervised exercise

training, smoking cessation, education about the disease and its management the inclusion of other components was less comprehensive as shown below:

|  |      |
|--|------|
| Supervised exercise training                   | 100% |
| Patient education: disease itself              | 100% |
| Patient education: management of exacerbations | 100% |
| Smoking cessation                              | 100% |
| Nutritional advice                             | 80%  |
| Psychological support                          | 70%  |
| Palliative care                                | 40%  |

Some programmes included input from smoking cessation officers, pharmacists, social workers, occupational therapists, anaesthetists, speech and language therapists, palliative care, life-coaching and alternative therapies. The staff mix delivering PRPs included physiotherapists in all cases, respiratory nurse specialists in 83%, physicians in 83%, occupational therapists in 67%, nutritionists in 58%, pharmacists in 58%, psychologists in 41%, and social workers in 33%.

v) Duration of PRP:

The duration of programmes varied in number of weekly sessions, duration of sessions and number of weeks over which programme was provided. However, the majority were delivered twice weekly for 7-8 weeks.

vi) PRP activity:

As is the case for access to spirometry for (timely) diagnosis and smoking cessation for reducing risk, access to PRP at time of diagnosis is essential to optimise disease management. The annual throughput of patients per programme varied from 20 to 60 with a total national annual throughput of 350 people. Given the prevalence of COPD, it is clear that there is currently insufficient capacity to provide this essential service to the large numbers of people with COPD.

#### **5.4.2 Pharmacological management**

##### **a) Influenza and Pneumococcal Vaccinations**

Influenza vaccination can reduce serious illness and death in patients with COPD by about 50% (Chapter 7). GPs reported that access to influenza and pneumococcal vaccines was easy / very easy for the vast majority (97.5%).

In the 2005/2006 influenza season, of 18-64 year olds with a health risk such as COPD, it was estimated that 28% had been vaccinated against influenza while 11% had a history of ever having pneumococcal vaccine.(132)

## b) AAT replacement

AAT replacement therapy is licensed in Ireland.

## c) Drug therapy

An analysis of medications suitable for treatment of people with COPD, prescribed for those  $\geq 35$  years, was conducted by the NCPE (see technical report). The analysis shows for those with GMS eligibility:

- There are a large number of people (148,000) aged  $\geq 35$  years on treatment consistent with obstructive lung diseases confirming the extent of the disease in Ireland.
- Over half (52%) were on short acting beta-2-agonists only. This may reflect either mild disease or under-treatment. The decrease in their use with increase in more regular inhaler use as age increases suggests treatment change with increasing disease severity.
- Overall, slightly more females than males were on treatment (21,559/100,000 vs 18,798/100,000). This may reflect a number of factors including health service utilisation patterns.
- There were differences in treatment rates by age group and drug category between the former health board areas. In the absence of patient registers, it is not possible to know if this is a diagnostic or a treatment issue.

In view of the large numbers of prescriptions, the proportion of potential adverse drug interactions were relatively small. For example, in the case of theophylline with ciprofloxacin this ranged from 1.2% to 3.5% (by former health board area) but does indicate an area for continuous awareness and education.

## d) Nebulisers:

Access to appropriate drug delivery mechanisms plays a key role in patient management. 58% of GPs reported that access to home nebulisers was easy / very easy.

The survey of LHOs provided information on the number of new nebulisers (i.e. not the number of new people commencing on nebulisers) issued between 2004-2006 (Table 5.3). The range varied widely despite the fact that the denominator used in each LHO was the total population rather than just those eligible for GMS. In the absence of patient registers, it is impossible to know if this is a diagnostic or treatment issue, but in the view of the extent of the variation, it suggests at least some variation in recording of consumables at LHO level.

**Table 5.3 New nebulisers issued in the community health setting 2004-2006**

| Year | Number | Range per 100,000 population | Rate per 100,000 population |
|------|--------|------------------------------|-----------------------------|
|------|--------|------------------------------|-----------------------------|

|             |             |               |            |
|-------------|-------------|---------------|------------|
| <b>2004</b> | <b>1447</b> | <b>6-264</b>  | <b>109</b> |
| <b>2005</b> | <b>1911</b> | <b>12-297</b> | <b>144</b> |
| <b>2006</b> | <b>2045</b> | <b>38-356</b> | <b>149</b> |

- 71% of the LHOs reported that they had arrangements for maintenance of nebulisers
- In relation to cleaning nebulisers, 93% of LHOs routinely advised patients about cleaning.

However, both the actual maintenance and cleaning arrangements varied widely (see technical report).

#### **5.4.3 Access to respiratory expertise**

Timely access to services including respiratory expertise when needed is essential for optimum patient care. The availability of such services can ensure that patients are cared for in the most appropriate setting, usually primary care, and receive the benefits of specialist advice that otherwise may necessitate hospital admission. Ease of access by GPs to such services was difficult/impossible in the following situations:

|                                      |       |
|--------------------------------------|-------|
| Pulse oximetry                       | 85%   |
| Rapid access respiratory clinic      | 86.3% |
| Respiratory Consultant review at OPD | 71.8% |
| Respiratory Nurse Specialist review  | 69.6% |

#### **5.4.4 Service Gaps /Deficits**

Availability of education and support services to aid patients' understanding of their disease is variable. This mitigates against appropriate self-management.

Most rehabilitation programmes do not accept GP referrals although best practice suggests that patients should be referred at the time of diagnosis, a stage in their illness when optimal benefit is possible. The small numbers of patients accessing rehabilitation programmes annually shows the extent of the unmet need.

While GPs report good access to vaccinations, in the absence of national information systems to record vaccination uptake in high risk patients, the impact of vaccination in Irish COPD patients cannot be determined.

The NCPE information suggests that prescribing is in keeping with best practice guidelines. However, there are unexplained variations in prescribing by different geographic areas and by gender.

There is a wide variation in the number of new nebulisers issued by LHOs. This requires national planning, standard setting and monitoring.

Nebuliser maintenance and cleaning are part of the duty of care of the supplier. There are wide variations in arrangements for cleaning and maintenance. This should be addressed and monitored in accordance with best practice.

Rapid access to specialist services is not uniformly available. This service gap mitigates against the management of people with stable COPD in the community health setting.

## **5.5 Component 4: Management of Exacerbations**

This section examines the needs of patients with severe COPD and those who require regular specialist respiratory care in conjunction with care provided by their GP and community supports. It also includes the use of long term oxygen.

Most patients who get exacerbations of COPD are managed at home by their GP. Improved access to community supports and services could increase this proportion even further. For the minority who require hospital admission, inadequate access to community supports can delay discharge.

Results of a Spanish survey showed that among patients who were hospitalised for a COPD exacerbation, many had modifiable risk factors, e.g. no rehabilitation in the past year (86%), poor inhaler technique (43%), no influenza vaccine (28%), under-prescription of long term oxygen therapy (LTOT) (28%), LTOT <15 hours/day (18%), current smoking (26%), and passive smoking among non smokers (21%).(133) An Irish prospective study in 1998 of acute hospital admissions of people with respiratory disease (85% had COPD) reported that only 21% had influenza vaccination that season and 31% were current smokers. In the same study only 42% knew the name of their illness and 38% knew the cause. Overall half ( 57%) of the admissions could have been avoided.(134)

Analysis carried out by the NCPE on 2006 GMS data showed that over 18,500 people aged  $\geq$  35 years were prescribed antibiotics in conjunction with inhaler therapy by their GPs. Although antibiotics can be prescribed for a variety of reasons, this figure may give some indication of the number of people with exacerbations of COPD who are treated in the community.

### **5.5.1 Patients with COPD exacerbation - community based services and supports**

The successful management of exacerbations of COPD in the Primary Care setting may require timely access to specialist services. GPs reported difficulty in accessing these

services, as shown in Table 5.4. Such access difficulties can mitigate against patient care in the community.

**Table 5.4 Ease of access to services and supports from GP perspective**

| Service                                       | Difficult/ impossible | Easy / very easy |
|---|-----------------------|------------------|
| Chest X-ray                                   | 11.8%                 | 75.6%            |
| Medical Assessment Unit                       | 55.8%                 | 29.2%            |
| Rapid access respiratory clinic               | 86.3%                 | 6.8%             |
| Physiotherapy                                 | 57.1%                 | 21.8%            |
| Occupational Therapy                          | 77.8%                 | 10.2%            |
| Clinical Nutritionist                         | 71.6%                 | 16.4%            |
| Public Health Nurse                           | 11.8%                 | 70.6%            |
| Home Help                                     | 29.1%                 | 40.2%            |
| Community Intervention Team/ Hospital at Home | 75.9%                 | 7.8%             |
| Community Unit/ District Hospital             | 70.0%                 | 15.9%            |

Although 70% of GPs found it difficult / impossible to access community beds for patients with COPD, half the LHO respondents said beds were available within the community, to which GPs could directly admit patients with an exacerbation of COPD. Where available, these beds were mainly in district hospitals and community nursing units. However the number of beds ranged from 1 to 63. Over one third (36%) of LHOs had step down beds available for hospitalised patients following an exacerbation of their COPD.

Almost four fifths (79%) of LHO locations could provide nursing care at short notice for patients in their own home during an exacerbation of their COPD. However, in 14% of LHOs this was limited to four patients or less. This care was provided under a number of different programmes/services including public health nursing staff (10), community intervention teams (2), hospital outreach team (2 - one of which was Hospital in the home (HiTH)), private provider (2 - one of which was HiTH) and intermediate care teams (2).

The home care provided by the LHO during an exacerbation of COPD varied from patient monitoring (9), assistance with activities of daily living (8), nebulised medication (6), oxygen provision (6), intravenous medication (2), education of patient and carer (1), chest physiotherapy (1) and home adaptation (1).

Only 11.5% respondents to the acute hospital survey had an early discharge or Outreach Programme for patients attending with an exacerbation of COPD.

### **5.5.2 Oxygen: Long Term Oxygen Therapy (LTOT)**

Oxygen therapy is one of the principal treatments for a select group of patients with severe COPD. Oxygen can be administered as long term continuous therapy (LTOT), ambulatory

oxygen during exercise and to relieve acute dyspnoea. LTOT should be administered for at least 15 hours per day but preferably for 24 hours.

Although the majority of those with COPD on LTOT are stable, these patients are an important COPD cohort. They should have been assessed by a respiratory specialist service including a consultant prior to their commencement on LTOT. However, 61% of GPs found it difficult / impossible to access LTOT assessment for their patients.

Table 5.5 shows the number of patients who were on LTOT at home, as reported by LHOs. The LHOs were asked to quantify the number of patients currently on home oxygen and the variations of this including nocturnal oxygen and oxygen for exercise only. The majority of patients on LTOT are likely to have COPD.

There were wide population differences in the rate of LTOT between the LHOs (note total population was used as the denominator used to determine rates, rather than GMS numbers). These variations raise questions about recording systems, under-diagnosis or over diagnosis, as there is no reason to believe that need varies so markedly between LHOs.

**Table 5.5 Number of Patients currently on Home Oxygen (per 100,000 population)**

|  | Number | Range /100,000   | Number /100,000 |
|--|--------|------------------|-----------------|
| Number currently receiving home oxygen (13 LHOs)                             | 2,230  | 50 – 289/100,000 | 132/100,000     |
| Number on home oxygen supply with ambulatory capacity (8 LHOs)               | 542    | 2 – 80/100,000   | 57/100,000      |
| Number on continuous home oxygen supply without ambulatory capacity (6 LHOs) | 326    | 9 – 83/100,000   | 40/100,000      |
| Number on nocturnal oxygen only (3 LHOs)                                     | 24     | 2- 9/100,000     | 7/100,000       |
| Number using oxygen for exercise only (3 LHOs)                               | 11     | 0 – 7/100,000    | 3/100,000       |
| Number of COPD patients on long term oxygen therapy (4 LHOs)                 | 195    | 15 – 83/100,000  | 45/100,000      |

Table 5.6 shows the number of new patients who were commenced on Home Oxygen Therapy between 2004 and 2006. Although numbers and rates have increased since 2004, this information indicates a need for a standardised system for recording and monitoring arrangements for LTOT at LHO level.

**Table 5.6 New patients commenced on Home Oxygen Therapy 2004-2006**

LHOs provided details of policies and procedures regarding provision and monitoring of

|      |               | Patients commenced on home oxygen (10 LHOs) | COPD patients commenced on home oxygen (2 LHOs) |
|------|---------------|---|---|
| 2004 | Number        | 467   | 21  |
|      | Range/100,000 | 5-62/100,000                                | 6-15/100,000                                    |
|      | Rate/100,000  | 36/100,000                                  | 10/100,000                                      |
| 2005 | Number        | 623   | 22  |
|      | Range/100,000 | 6-163/100,000                               | 8-14/100,000                                    |
|      | Rate/100,000  | 49/100,000                                  | 11/100,000                                      |
| 2006 | Number        | 713   | 25  |
|      | Range/100,000 | 16-152/100,000                              | 7-16/100,000                                    |
|      | Rate/100,000  | 56/100,000                                  | 12/100,000                                      |

LTOT. Details of who could prescribe home oxygen initially and on an ongoing basis are shown in Table 5.7 (multiple answers were allowed).

**Table 5.7 Prescription of Oxygen for Home Use**

|                              | Initial Prescription | Prescribe ongoing Oxygen |
|------------------------------|----------------------|--------------------------|
| Hospital Consultant          | 93%                  | 78%                      |
| Respiratory Nurse Specialist | 7%                   | 7%                       |
| General Practitioner         | * 78%                | 86%                      |
| Physiotherapist              | 7%                   | 7%                       |

\*In one instance GP could only prescribe oxygen by cylinder

Half of the LHO respondents had difficulty with the level of detail provided on home oxygen prescriptions. These included:

- inadequate information e.g. flow rates not always included, type of oxygen not indicated, detail of oxygen saturation levels not provided
- lack of communication between hospital and community: discharge letter may only say "on oxygen therapy", prescriptions not seen.

Arrangements for follow-up of patients on LTOT varied considerably and included reviews by a GP, consultant or public health nurse. In 59% of acute hospitals, physiotherapists reported that they were involved in oxygen assessment of patients. 89% of respiratory nurse specialists reported that they were involved with inpatient oxygen assessment, while 75% were involved with outpatient oxygen assessment.

As part of their oxygen services:

- 64% (9) LHO respondents were aware of a policy on the provision of portable oxygen cylinders. Those who could prescribe portable oxygen included Consultant Physician (5), Respiratory Consultant (1), Consultant or GP (4), PHN with GP (1).
- 64%(9) LHO respondents were aware of arrangements for urgent (i.e. in < 24 hours) provision of oxygen in the home.
- 86%(12) were aware of arrangements for ongoing maintenance of oxygen appliances.
- 57%(8) were aware whether minimum requirements were adhered to in the installation of an oxygen supply in the home e.g. minimum number of points and minimum length of tubing.

### 5.5.3 Acute hospital services

#### a) Non-Invasive Ventilation (NIV) Services

The majority in NIV is provided as part of acute hospital services. In hospitals with NIV, the main locations within hospitals where it was available were:

|                   |       |
|-------------------|-------|
| ED                | 38.5% |
| MAU               | 15.4% |
| All medical wards | 26.9% |
| Respiratory ward  | 19.2% |
| HDU               | 19.2% |
| ICU               | 84.6% |

Some respondents also stated that NIV was available in CCU (4), throughout entire hospital (1), special care unit (1), one specified medical ward (2), observation area of all wards (1), and a combined CCU/ICU/HDU (1).

Almost three quarters (73%) of acute hospitals had written policies on NIV. These included three in draft format.

78% of respiratory nurse specialists reported that acute NIV is provided at High Dependency Unit (HDU) or ward level. However, only 10% (2) provided support for patients on NIV at home. 10% of respiratory nurse specialists worked in hospitals which did not have NIV.

Detailed information in relation to physiotherapy involvement in NIV is available in the Physiotherapy Technical report. In 50% of locations which responded to the physiotherapy survey, NIV was used as an adjunct to physiotherapy treatment. In some instances, NIV services were physiotherapy-led.

#### b) Other Acute Hospital Services

Inpatient activity for COPD by network region is shown in Table 5.8. Inpatient discharge rates vary considerably between networks from 364/ 100,000 in the South to 723 / 100,000 in Dublin South. Lengths of stay also vary. As there is no reason to believe that COPD prevalence varies across the country, other factors such as service configuration most likely contribute to these variations.

The availability of specific units in acute hospitals can influence both whether a person is admitted to hospital and their length of stay. Based on the acute hospital survey, the following units were available:

- Medical Assessment Unit 30.8%
- Dedicated respiratory ward 19.2%
- Dedicated non invasive ventilation ward 11.5%

None of the respondent hospitals had a solely medical high dependency unit (HDU) while five (19%) had a mixed HDU. A number of others relied on ICU and /or CCU.

**Table 5.8 Inpatient Activity for COPD (Principal Diagnosis) Aged 35+ 2006**

| Network         | Inpatient Discharges (N)<br>Rate/100,000 total pop | Bed Days Used | Mean LOS |
|-----------------|--|---------------|----------|
| North-East      | 1,068<br>580/100,000                               | 9,718         | 9.1      |
| Dublin North    | 1,105<br>466/100,000                               | 13,536        | 12.2     |
| Dublin South    | 1,251<br>723/100,000                               | 17,109        | 13.7     |
| Dublin Midlands | 1,598<br>410/100,000                               | 19,742        | 12.4     |
| South-East      | 1,579<br>693/100,000                               | 14,093        | 8.9      |
| South           | 1,119<br>364/100,000                               | 11,371        | 10.2     |
| Mid-West        | 1,051<br>596/100,000                               | 9,102         | 8.7      |
| West North-West | 1,941<br>597/100,000                               | 16,546        | 8.5      |
| Total           | 10,712<br>530/100,000                              | 111,217       | 10.4     |

Source: HIPE

The access which patients with COPD have to some specialist services, traditionally based in acute hospitals, is shown in Table 5.9 below. These are services which patients may need at any stage of their COPD. It can be seen that access to some services is limited.

**Table 5.9 Access to specialist services**

| Patients with COPD | Respiratory Specialists | Nurse | Palliative Care services |
|--------------------|-------------------------|-------|--------------------------|
| All in patients    | 61.2%                   |       | 65.4%                    |

|  |       |       |
|--|-------|-------|
| All out patients                                 | 57.7% | 23.1% |
| ED/ MAU  | 53.8% | 11.5% |
| Referrals by GPs                                 | 26.9% | 3.8%  |
| Only In-patients under care of respiratory team  | 7.7%  | 3.8%  |
| Only Out-patients under care of respiratory team | 7.7%  | 3.8%  |

42% of Respiratory Nurse Specialists provide palliative care for in-patients with COPD and for 15% of out-patients. In 35% of acute hospitals physiotherapists provide palliative care.

### c) Hospital Admission Policies

Based on information from 86% of the hospitals with respiratory consultants (personal communication - ITS), for patients admitted as inpatients with respiratory problems:

- 5.5% were always admitted under the care of the respiratory team
- 78% were admitted under the care of the respiratory team where the patient had previously been an in-patient under their care
- 44% were admitted under the care of the respiratory team if the person had previously been under their care as an out-patient.

Specifically for COPD, 22% admitted these patients under the care of the respiratory team while an additional location did so if the patient was in type 2 respiratory failure or it was their first hospitalisation with COPD.

#### 5.5.4 Service Gaps/Deficits

Primary Care is the appropriate setting for the majority of patients with an exacerbation of COPD. However, for this to be effective, if required rapid access to respiratory expertise and services should be available.

If COPD services are to be re-orientated to Primary Care, care in the community needs to be enhanced, standardised and monitored. Support is needed from a range of specialist services e.g. physiotherapy (essential in the event of chest infections), community nursing, community beds, outreach and early discharge programmes. Otherwise for some patients with exacerbations, acute hospital admission and unnecessary lengths of stay will continue.

Use LTOT is a major event in a patient's life and is costly to the health service. Prescription of LTOT for people with COPD should be based on advice from a respiratory consultant. The variation in numbers of people on LTOT who are known to the LHO indicates the need for implementation of standards and monitoring of this service.

All hospitals who accept acute respiratory admission should have arrangements for both NIV and invasive ventilation.

## 5.6 Human Resources

Best practice care of people with COPD requires multidisciplinary general and specialist respiratory staff, who work across locations and who have continuous professional training.

The overview of the four components (Assess and Monitor Disease, Reduce Risk Factors, Manage Stable COPD, Manage Exacerbations) shows service gaps in the acute and community settings and inadequate service integration. In some cases the service gaps reflect lack of personnel and in others lack of training and service integration between the different care settings.

Some of the service gaps identified include:

- Primary and Community Respiratory care: Given that it is in the community setting where most of the services for people with COPD are delivered, there are clear gaps in services e.g. unnecessary hospital referrals for diagnostics and admission, lack of specialist respiratory expertise and advice for those working in the community. An important development to maintain care in the community setting is the development of multi-disciplinary Primary Care Teams (PCTs), with the appropriate skill mix and access to services. Just under one-fifth of practices in the GP survey reported that they were part of a primary care team but a further one-third believed they would be within the next year.
- Acute setting: In the acute setting, the majority of emergency admissions are via generic ED services. Currently in acute hospitals many patients with respiratory conditions are managed by non-respiratory medical teams both as inpatients and as out-patients.

This chapter shows the importance of timely access to respiratory expertise:

- Currently there are 35 whole time equivalent (WTE) respiratory consultants (i.e. 1 per 120,000 population compared with the UK norm of 1 per 50,000 population). Almost half of Ireland's respiratory consultants are based in Dublin.
- Thirty-five respiratory nurse specialists are members of the respiratory Nurses Group (ANAIL).
- Some details of the numbers of respiratory scientists are provided both in the acute hospital survey and respiratory scientists survey (see technical reports).
- There are 77 WTE Smoking Cessation Officers.
- The majority of physiotherapy services for people with COPD are provided either by the general physiotherapy service or as part of the respiratory service caseload. The estimated WTE of physiotherapists involved with people with COPD is not known.
- Five acute hospitals, based on the results of the physiotherapy survey, have no provision for outpatient physiotherapy services. That survey also indicated that there

are no dedicated physiotherapists providing a service for COPD inpatients in any of the acute hospitals.

- The number of other allied professions with a key role in the care of people with COPD is unclear.

The data above does not reflect how resources are distributed around the country, settings or locations for example:

- The availability of specified staff on weekdays 9am-5pm and the availability of specified staff on weekends 9am-5pm to treat acutely ill COPD patients is shown in Table 5.10. This data was provided from the acute hospital survey and is based on locations i.e. not numbers of staff or WTEs.

**Table 5.10 Availability of staff during week day and week ends**

| Staff                                 | Weekdays 9am-5pm | Weekends 9am-5pm (N)    |
|---------------------------------------|------------------|-------------------------|
| Respiratory Consultants               | 46.2%            | 3 +3 if on general rota |
| Specialist Registrar                  | 30.8%            | 2+1 if on general rota  |
| SHO                                   | 30.8%            | 1+1 if on general rota  |
| Intern                                | 27.0%            | 0+1 if on general rota  |
| Respiratory CNS                       | 50.0%            | 1+1 emergencies         |
| Ward Nurses with Respiratory training | 27.0%            | 1+1 emergencies         |
| Physiotherapist                       | 53.8%            | 34.6%                   |
| Medical Social Worker                 | 15.4%            | 0                       |
| Occupational Therapist                | 19.2%            | 0                       |
| Clinical Nutritionist                 | 15.4%            | 0                       |

- Just over half (54%, 14) of the locations had respiratory consultants on staff ranging in number from 0.2WTE to 5.0WTE
- 31% (8) of locations had Respiratory Registrars/Specialist Registrars
- 73%(19) had Respiratory Nurse Specialists (RNS)
- Only one site had an RNS working solely with COPD patients (0.5 WTE) and this post was funded by industry
- Ward Nurses with Respiratory training were available on 62% of sites ranging in number from 1-25
- Palliative Care Nurse Specialists were available in 81% of locations
- Other staff working in Respiratory medicine included: Physiotherapists 54%, Medical Social Worker 15.4%, Occupational Therapist 19% and Clinical Nutritionist 15.4%

### 5.6.1 Service Gaps / Deficits

Sufficient staff numbers, both general and specialist respiratory, working across locations with ongoing continuous professional training are required to deliver services to enable patient care in the most appropriate setting.

## **5.7 Conclusion**

The current approach to COPD health services is fragmented. This chapter shows that there are wide variations in diagnostic and treatment services. While there are many examples of good practices in some locations (see Chapter 6), in other locations there is an over-reliance on episodic acute hospital care which is not well equipped to meet the requirements of effective COPD care. International and national evidence indicates that many patients with COPD have sub-optimal care including under-diagnosis, care in inappropriate settings, missed opportunities for prevention, evidence-based guidelines not followed due to relative lack of services, inadequate patient self-management support, and lack of integration of care between the primary care and hospital settings.

## Chapter 6 Consultation

### Key Points

- COPD patients often have a poor quality of life. They experience psychological distress and social isolation.
- Patients need access to local specialist services. This includes timely diagnosis, treatment, rehabilitation and monitoring of their condition.
- There is geographic inconsistency in service provision.

### 6.1 Introduction

Consultation with stakeholders is a key component in forming a strategic plan for COPD. The consultation process considered the views and experiences of patients with COPD, professional bodies, individual service providers and voluntary organisations. Views were sought on the needs of COPD patients, strengths and weaknesses of current services and recommendations as to how services could be improved. Contributors were asked to highlight any local studies or initiatives that were taking place which would be relevant to the development of the strategy. Information on these initiatives has been summarised as examples of what is currently happening around the country. Many of the initiatives are pilot schemes, some are project proposals and some are best practice services that serve specific catchments. Information on these initiatives was used in the writing of this strategy.

### 6.2 Stakeholders' Views

#### 6.2.1 Contributors

A questionnaire (see appendix) was sent to a number of organisations and key decision makers. Some organisations provided single coordinated written responses while other organisations provided multiple replies from a number of relevant stakeholders within the organisation. There were 226 questionnaire responses and a number of additional submissions and documented conversations (the list of responders is provided in Appendix 6).

A number of relevant health service providers and carers were also invited to contribute to the survey consultation process; this included targeting GPs, acute hospital staff, and respiratory scientists.

Some contributors provided information in phone calls or email communication. Submissions were also made on work being undertaken and proposals for service development.

The range of service providers who responded was comprehensive and included the following: GPs, respiratory nurse specialists, clinical nurse managers, chartered physiotherapists, occupational therapists, social workers, nutritionists, dieticians, hospital consultants, directors of nursing, directors of public health nursing, public health and community nursing staff, smoking cessation officers, pulmonary scientists and care of the elderly staff.

A patient focus group was arranged via an existing patient support group. Patients also made written submissions and were in contact by phone and e-mail.

### **6.2.2 Themes**

This section outlines the main themes from the stakeholder consultation, where the questionnaires asked about the needs of patients with COPD and the barriers they faced to better care and management. The needs detailed by the consultation are summarised below:

- Timely access to local specialist services. This includes timely diagnosis, treatment and access to review, monitoring and follow-up
- Patient education for physical therapies, pulmonary rehabilitation, medication, disease progression and entitlements
- Rapid access to treatment for acute exacerbations
- Poor quality of life for patients
- Psychological distress and social isolation
- Smoking cessation support
- Need for better home support, adaptation, transport and financial support.

The lack of services to address these issues were seen as barriers to the best care for patients with COPD.

#### **a) Timely access to local specialist services, including timely diagnosis, treatment and access to review, monitoring and follow-up**

Multiple examples were provided of how patients and staff need timely and responsive services. The lack of a national/standardised treatment protocol has led to inconsistent service provision around the country with differing models of care and problems of service integration. At present the delivery, quantity and quality of services vary by geographic region. Specialist services and staff are crucial to patient outcome. There are services providing best practice care and integrated care covering assessment, diagnosis, early intervention, treatment, pulmonary rehabilitation and access to review, monitoring and follow-up and access to palliative care if necessary. These services have multidisciplinary teams and outreach services. The issue is the geographical variation in access to these services.

Access to a multidisciplinary team approach is recognised as best practice for the management of COPD (ref). There is a need for access to specialist respiratory care at a designated centre with a clinical nurse specialist in respiratory care, a respiratory physiotherapist, and an occupational therapist. A psychologist, clinical nutritionist and public health nurse are also seen as necessary in specialist centres.

Some patients have difficulty accessing services. This can be for a number of reasons including the lack of a respiratory specialist available locally, long waiting times/delays for the Medical Assessment Unit, specialist services or outpatient departments and the need to access respiratory expertise through ED. In some areas access to equipment, oxygen and home adaptation is an issue.

Pulmonary Rehabilitation is required by all patients diagnosed and treated for COPD.

Outreach Programmes which provide “hospital in the home” care are available in some areas and are particularly suited to this condition where frequent exacerbations often lead to ED admissions. This programme encourages admission avoidance and/or early discharge, access to local monitoring and follow-up, and review. Some services have direct access for patients to OPD.

GP's have indicated their willingness to provide dedicated assessment, treatment and follow-up as part of a programme for chronic disease management in primary care, a form of shared care model. This would facilitate early access to assessment, diagnosis and care in order to prevent deterioration in the patient's condition.

#### **b) Patient education on physical therapies, medication, disease progression and entitlements**

Stakeholders stated that information and understanding of COPD among patients was poor. Education and ongoing support lead to a greater sense of empowerment and control of the condition and symptoms.

The importance of primary and secondary prevention were emphasised including the need for smoking cessation programmes, the importance of the provision of medication for the control and relief of symptoms, influenza vaccinations, training and education for physical therapies, O2 and inhaler technique. Poor information on services available and progression of condition was a barrier to best care for patients. Literacy proofing was recommended for all materials produced and distributed for patients and families.

#### **c) Rapid access to treatment for acute exacerbations**

Immediate access to medical support for acute exacerbations was identified as a need of patients with COPD. Patients often experience frequent exacerbations, poorly controlled symptoms, long waiting times, lack of beds in winter and revolving door ED. The model of care proposed for timely access differed among respondents and geographical regions and reflects the heterogeneity of services currently in existence. Solutions proposed include development of fast track or direct access to ED departments, Medical Assessment Units, Rapid access clinics (all hours) and enhanced primary care services.

#### **d) Poor quality of life for patients**

Many stakeholders commented on the poor quality of life of many patients with COPD. The issues noted most often were the following; poor housing, poor social circumstances and supports, poor transport, poor seating and disabled parking, and poor health status generally. COPD interferes with the capacity to conduct activities of daily living. This impacts on family members as well. Many patients have shortness of breath with excess sputum production, low exercise tolerance and recurrent infections. The need for LTOT when indicated can also severely restrict patient's mobility outside of the home or hospital.

#### **e) Psychological distress and social isolation**

The poor quality of life many COPD patients endure has an effect on their level of psychological distress, including anxiety, fear and depression. In some cases, there is also a level of stigma and guilt due to the knowledge that smoking has caused their condition and due to their inability to quit smoking even when the condition is advanced. There is social isolation and a fear of leaving the house in case they get an exacerbation or from the embarrassment of carrying oxygen.

Social support is important in overcoming this issue and counselling and support groups need to be available. Support groups encourage knowledge and expertise in patients and an understanding of the disease process and provide much needed social support.

#### **f) Needs for better home support, adaptation, transport and financial support**

Many patients with COPD need home adaptation and home help. Staff and support groups identify access to aids and appliances and help with activities of daily living as a need of patients and a lack of these as a barrier to better care and management.

Financial concerns are a problem for those above GMS means test level where the cost of medications and home adaptation is often beyond their means. People with COPD are not entitled to a long term illness card with its associated benefits.

### **6.2.3 Patients' views**

The patients' view should be taken into consideration as COPD often leaves individuals socially isolated and suffering poor health. The patient's experience of the current services and the progression of the disease process can provide insight and knowledge to further develop the strategic response.

Focus Group methodology was used to gather information on COPD patient's experiences and needs. There are two dedicated support groups for patients with COPD in the country. These groups are a social support to COPD patients and function as a means of passing on information about the condition and services and how to access them. Permission was granted to conduct a focus group with the members of these groups. One focus group has been conducted with nine members of one group. These individuals are broadly representative of COPD patients and are diverse in gender, age, current medical status and urban/rural area of health services.

The focus group was conducted during the day using rooms in a local health centre. A facilitator and scribe were used and the session was taped. The focus group lasted approximately 1.5 hours including refreshments and introductions. Some participants provided written notes and comments that are incorporated in the results.

The following set of topics was used to guide the focus group discussions. Participants were encouraged to discuss any other issues they considered important.

- How does this group function and what type of issues do you discuss and address within the group?
- What are the main barriers for people with COPD achieving a good quality of life?
- What are the strengths of the current services for people with COPD?
- What are the weaknesses in the current health services for people with COPD?
- What recommendations would you make to improve services/quality of life for people with COPD?
- Are you aware of any specific initiatives for COPD patients in your area?
- What are the greatest needs of people with COPD?

The views of patients can be summarised into five main themes:

- Geographic inconsistency in service provision
- Clarity of diagnosis
- Need for education regarding condition, progression and physical therapies
- Psychological Issues
- Quality of Life

#### **a) Geographic inconsistency in access to service provision**

Within the focus group there was considerable variation between services available in neighbouring geographical areas. Referral patterns and patient journeys were different with some individuals progressing in a timely manner through diagnosis, specialist treatment, pulmonary rehabilitation and continued monitoring. Others experienced delayed or vague diagnosis, lack of specialist care, frustration, increased number of acute exacerbations and poor access to rehabilitation and monitoring. This pattern repeated itself with regard to access to home treatments, oxygen, outreach and community services, psychological support, home help and adaptation and allied health professional input.

*“(M1) We need an outreach department, where you would have a complete respiratory team, a specialist nurse, a physio, a complete team, save you going to the hospital, could come to the house. The thought of going to the hospital can make you almost worse”*

#### **b) Diagnosis**

Some patients were of the opinion that getting a diagnosis had been a difficult and prolonged process for them. They had been diagnosed with conditions such as bronchitis and asthma for many years. The patients felt this delayed any steps they might have taken to improve their health and slow the progression of disease. The majority of the group had ceased smoking but this had only occurred relatively recently (within the last 5-8 years approximately). They were aware that most of the damage had already been done. The GP is often the first point of contact for patients and it was felt that some GPs could be better informed about COPD or more willing to refer to specialist services (where they exist) for diagnosis and treatment.

#### **c) Education**

All the patients agreed that education and information about their condition was essential for them. It was one of their motivations for participating in a regular patient support group as it gave them access to information and support. Education is often provided at the time of acute exacerbation when the patient is in hospital. Often the patient cannot remember instructions and then is too embarrassed to follow-up and ask again. Public service education and awareness is also helpful. Reports in the media help to explain the condition to patient's family and friends and create understanding and awareness of the condition.

#### **d) Psychological Issues**

This is an area that emerged strongly from the consultation. The patient with COPD often experiences depression, anxiety, panic attacks and a loss of independence and autonomy as a direct result of their condition and the constraints it places on them. People are sometimes housebound, are unable to move about freely, have coughs that embarrass them, difficulty breathing and cannot eat or participate in many activities where crowds, smoking or strong smells are present. There is a great need for psychological supports to help with these

feelings of stigma and isolation. Patients describe how it feels to not look 'sick' but know you are not going to get better.

*“(M1) There is a fear of going out and I mean I have met people who like myself have to carry a nebuliser with them all the time but they won't actually use it, in the street. (M2) That's pride, that's pride. (M1) That's terrible like, they won't go out because they have oxygen on, they won't use it in the street”*

#### **f) Quality of life**

The patients described the reduction in their quality of life very clearly. The normal activities of daily living are challenging for them. Poor symptom control and the number of acute exacerbations compound this. Difficulties with daily living include; being unable to climb stairs, maintain the house, attend appointments, continue farming/ employment and accessing and using transport. The patients expressed frustration at being unable to do simple domestic duties, cooking, cleaning, home maintenance. The access to home help, home adaptation and financial supports was inconsistent and information on entitlements was not readily accessible or different for adjoining regions. Transport can be a practical issue for some, disabled parking disks can be difficult to obtain, and public transport is time consuming and very irregular. Patients would like to be able to access occupational therapists who could help with house adaptation and information about entitlements. Home help support is difficult to access for the under 65 age group and home support packages would improve quality of life for these patients. (For some patients the lack of computer broadband access in rural areas added to their frustration. They spent a large amount of time at home and the internet is a source of information, support and community for them.)

*“(F1) I am sort of still looking after my family, running on about 50% on what I was three years ago, and its very hard for me to cope with that because my family can't see the fact that I have dropped back 50% and yet they see all the things that need to be done but nobody seems to realize I am no longer able to do them it's very hard to get that through to them that I can no longer do them”*

### **6.3 Initiatives**

#### **6.3.1 Sources of information**

The consultation process highlighted a number of initiatives that are occurring around the country. This included projects that had been set up locally, often on a pilot basis or without any additional funding or commitment to ongoing funding. Some proposals for initiatives were included which had not yet proceeded due to funding difficulties. Information that had been gathered for a chronic disease support pilot and information gleaned from specific service provider surveys has also been included in this section.

The consultation process and the questionnaire on service provision identified a number of initiatives for the management of COPD occurring throughout the country. The following section attempts to reflect and summarise the added efforts and determination of services and personnel to provide care and management to COPD patients and their families. Over time some initiatives become part of routine service and may no longer be reflected in the following examples but are no less important in addressing the needs of patients and service development.

### **6.3.2 Examples of initiatives**

#### **Supported home respiratory care**

Provision of oxygen, non-invasive ventilation, nebuliser and IV therapy in the patient's home. This initiative is provided in different instances by dedicated outreach services from community or primary care or by the hospital or specialist unit.

#### **Integrated care pathway for COPD**

A nurse specialist programme in asthma and integrated care pathway includes some patients with COPD. This integrated care pathway has a number of stages which include emergency room presentation, inpatient evaluation and outpatient management. This pathway is co-ordinated between the nurse specialist, ward teams and the physiotherapy group.

There is a Respiratory Assessment Unit including multi-disciplinary team in one acute hospital, led by respiratory nurse and respiratory physiotherapist. This offers community outreach with follow-up clinics and onward referral to pulmonary rehabilitation programme

#### **Nurse delivered COPD education in hospital**

Respiratory nurse specialist services provide a support and education service for inpatients and outpatients for patients with COPD and their families. There are seminar lectures twice a week for four weeks on all aspects of COPD and its care.

#### **COPD support group**

A peer based support group that also has health care professionals as members provides education, information, social support, and advocacy.

#### **Self-management programme and telephone support**

Pulmonary outreach for the elderly is a pilot project that facilitates early discharge of patients who have been admitted with uncomplicated acute exacerbations of COPD by providing active treatment in patient's home, including telephone support.

#### Long-term oxygen assessment clinic

Clinics provides long-term oxygen assessment, ordering of equipment and education. As COPD patients can be harmed by ambulance personnel, accident and emergency department staff and other staff giving them 100% oxygen, patients now carry an O2 alert card. This has their personal details and indicates the level of oxygen appropriate to their needs.

The enthusiasm and dedication of staff in creating opportunities to improve services for COPD patients locally is to be commended. COPD patients have long been overlooked group. There is clear evidence of commitment to innovation and improving patient care. The initiatives were usually based and developed around an existing hospital service. These initiatives have been evaluated and outcome measures indicate reductions in the number and severity of exacerbations and decreases in the number of admissions and the average length of stay. These have remained regional initiatives, highlighting the difficulties in rolling out services to improve equity and access for all patients nationwide, in the absence of a national strategy, with a coordinated approach and commitment to ongoing funding.

## 6.4 Conclusion

It is clear from the results of the stakeholder consultation that there is a great degree of agreement between the service providers and the COPD patients as to what is required to improve and develop services i.e.

- access to services that provide specialist diagnosis, treatment and monitoring
- access to specialist treatment at the time of acute exacerbation
- recognition and support for psychological sequelae
- practical interventions and education to improve quality of life.

These priorities identified through the consultation process also include the need for consistent service provision across geographical regions, thus achieving a better equity of access than currently exists.

## Chapter 7. Clinical Guidelines

### 7.1 Introduction

Evidence based guidelines are systematically developed statements to assist practitioner and patient decisions about appropriate health care for specific clinical circumstances and diseases. An evidence based approach to the management of COPD should:

- Prevent and limit the progression of COPD, through prevention, early detection, treatment and effective management
- Slow the onset of complications which can cause severe disabilities and can be life threatening
- Reduce preventable hospital admissions
- Reduce variations in care which occur between different clinicians, health services and locations/settings.

The National COPD Strategy Group reviewed international guidelines as part of its task to develop a strategy for the management of COPD.

The Global Initiative for Chronic Obstructive Lung Disease (GOLD) was formed by WHO along with the US National Heart, Lung, and Blood Institute in 1998 in an effort to bring more attention to COPD, its management, and its prevention. The first step in the GOLD programme was to prepare a consensus report, Global Strategy for the Diagnosis, Management, and Prevention of COPD, published in 2001.<sup>(135)</sup> Yearly updates are produced, which are based on publications from the previous years. GOLD is also part of Global Alliance for Respiratory Disease (GARD), a voluntary alliance of national and international organisations, institutions, and agencies working towards the common goal of improving global lung health.

The Strategy Group considered the GOLD Guidelines to be the most appropriate on which to base these Irish guidelines, while also using relevant components from the other English language guidelines.<sup>(15)</sup> Summary points are in Appendix 7.2.

### 7.2 Approach to the management of COPD

An effective COPD management plan is multi-factorial involving both pharmacological and non-pharmacological therapies. The four components of the GOLD approach are:

- Assess and Monitor Disease
- Reduce Risk Factors
- Manage Stable
- Manage Exacerbations

Management of Mild (Stage 1) and Moderate (Stage II) COPD involves the avoidance of risk factors to prevent disease progression and pharmacotherapy as needed to control symptoms. Severe (Stage III) and Very Severe (Stage IV) COPD require the integration of several different disciplines, a variety of treatment approaches, and a commitment to the continued support of the patient as the illness progresses. (see Table 7.1).

In addition to patient education, health advice and pharmacotherapy, patients with COPD may require specific counselling about smoking cessation, instruction in physical exercise, nutritional advice, and continued health care support. Not all approaches are needed for every patient. Assessing the potential benefit of each approach at each stage of the illness is a crucial aspect of effective disease management.

The impact of COPD on an individual patient depends not just on the degree of airflow limitation, but also on the severity of symptoms. There is an imperfect relationship between the degree of airflow limitation and the presence of symptoms. Although spirometry, which is used to measure airflow obstruction, does not fully capture the impact of COPD on a patient's health, it remains the gold standard for diagnosing and monitoring its progression.

**Table 7.1 Stages of COPD based on spirometry**

|   |
|---|
| <p>Stage I: Mild COPD: <b>Individual may not be aware that his/her lung function is abnormal.</b></p> <ul style="list-style-type: none"><li>• <b>Mild airflow limitation (<math>FEV_1/FVC &lt; 70\%</math>; <math>FEV_1 \geq 80\%</math> predicted) and sometimes, but not always chronic cough and sputum production.</b></li></ul>  |
| <p>Stage II: Moderate COPD: <b>Patients typically seek medical attention at this stage because of chronic respiratory symptoms or an exacerbation of their disease.</b></p> <ul style="list-style-type: none"><li>• <b>Worsening airflow limitation (<math>FEV_1/FVC &lt; 70\%</math>; <math>FEV_1</math> 50% to 80% predicted), with shortness of breath typically developing on exertion.</b></li></ul> |
| <p>Stage III: Severe COPD: <b>Further worsening of airflow limitation (<math>FEV_1/FVC &lt; 70\%</math>; <math>FEV_1</math> 30% to 50% predicted), greater shortness of breath, reduced exercise capacity, and repeated exacerbations which have an impact on a patient's quality of life.</b></p>  |
| <p>Stage IV: Very severe COPD: <b>At this stage, quality of life is very appreciably impaired and exacerbations may be life-threatening</b></p> <ul style="list-style-type: none"><li>• <b>Severe airflow limitation (<math>FEV_1/FVC &lt; 70\%</math>; <math>FEV_1 &lt; 30\%</math> predicted or <math>FEV_1 &lt; 50\%</math> predicted plus chronic respiratory failure).</b></li></ul>                 |

Disease prevention is the ultimate goal. Once COPD has been diagnosed, effective management is aimed at the following:

- Relieve symptoms
- Prevent disease progression
- Improve exercise tolerance
- Improve health status
- Prevent and treat complications
- Prevent and treat exacerbations
- Reduce mortality
- Prevent or minimise side effects of treatment.

Achieving these goals in patients with COPD can be challenging due to co-morbid conditions. Smoking cessation is a goal throughout the management programme.

Educating patients, health professionals and the public that cough, sputum production, and especially breathlessness are not trivial symptoms is an essential aspect of the public health care of the disease.

As stated in previous chapters, COPD is a preventable and treatable disease characterised by airway inflammation and airflow limitation that is not fully reversible and with significant extra-pulmonary effects.

The four components set out in GOLD are used to structure this chapter. Other sources are referenced as appropriate.

### **7.3 Component 1: Assess and Monitor Disease**

#### **Key Points (GOLD)**

- COPD should be considered in any patient who has dyspnoea, chronic cough or sputum production, and/or a history of exposure to risk factors for the disease.
- The diagnosis should be confirmed by spirometry.
- The presence of a post bronchodilator  $FEV_1/FVC < 70\%$  and  $FEV_1 < 80\%$  predicted confirms the presence of airflow limitation that is not fully reversible.
- Health care workers involved in the diagnosis and management of COPD patients should have access to spirometry.
- Assessment of COPD severity is based on the patient's level of symptoms, the severity of the spirometric abnormality, and the presence of complications.
- Measurement of arterial blood gas tensions should be considered in all patients with  $FEV_1 < 50\%$  predicted or clinical signs suggestive of respiratory failure or right heart failure.

- COPD is usually a progressive disease and lung function can be expected to worsen over time, even with the best available care. Symptoms and objective measures of airflow limitation should be monitored to determine when to modify therapy and to identify any complications that may develop.
- Co-morbidities are common in COPD and should be actively identified. Co-morbidities often complicate the management of COPD, and vice versa.

### **7.3.1 Initial diagnosis**

Diagnosing COPD depends on clinical judgement based on a combination of history, physical examination, functional assessment and confirmation of the presence of airflow obstruction using spirometry.(136)

Crucially, diagnosis depends on considering COPD in the first place. Such a diagnosis should be considered in any patient who has dyspnoea, chronic cough or sputum production, and / or a history of exposure to risk factors for the disease, especially cigarette smoking. Algorithm A shows this in greater detail. These symptoms are not diagnostic in themselves although the presence of multiple symptoms increases the likelihood of a diagnosis of COPD. Spirometry is needed to establish the diagnosis.

### **7.3.2 History, functional assessment and physical examination**

A detailed history and functional assessment of a patient thought or known to have COPD should include the factors listed in Algorithm A.

A physical examination is rarely diagnostic in COPD but it is an important part of patient care. In some patients there may be no abnormal physical signs.(137) In others a number of physical signs may be present (see Appendix 7.3). Absence of physical signs does not exclude a diagnosis of COPD.

### **Co morbidities**

Risk factors such as smoking are common to many of the leading causes of death and of chronic disease. Risk factors interact, often in a multiplicative fashion. Risk factors cluster in individuals as do chronic diseases such as COPD.

Co-morbidities can be categorised as:

- Common pathway co-morbidities
- Complicating co-morbidities
- Co-incidental co-morbidities
- Inter-current co morbidities.

Co-morbidities have previously been discussed in Chapter 4. Smoking, in addition to causing COPD, can impact on all of the above.

### 7.3.3 Assessment of severity

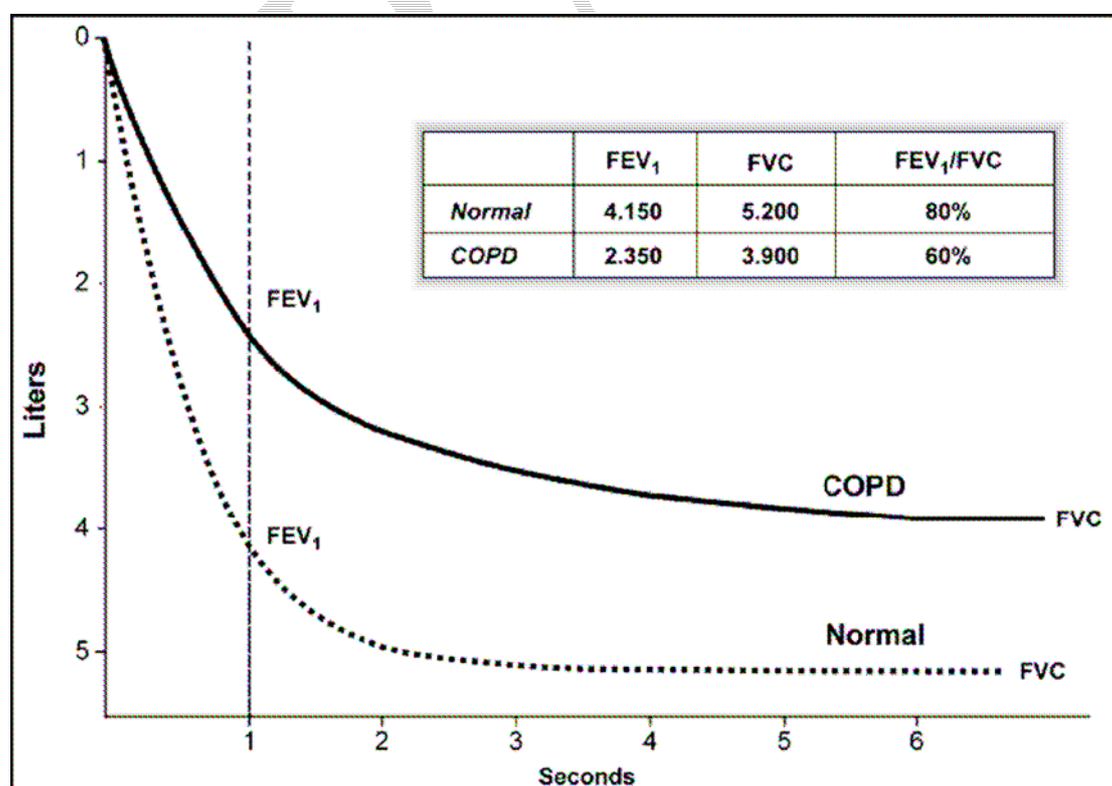
Assessment of COPD severity is based on the severity of the spirometric abnormality (Table 7.1), the patient's level of dyspnoea (Table 7.2 MRC Dyspnoea Scale) and the presence of complications such as respiratory failure, right heart failure, weight loss, and arterial hypoxaemia.

The BODE composite score (Body mass index, Obstruction, Dyspnoea and Exercise capacity) is a relatively simple approach to identifying disease severity. It is a better predictor of subsequent survival than any component singly.(138) As a tool it is still under investigation.

#### a) Measurement of airflow limitation (spirometry)

Spirometry, as an objective measure of how an individual inhales and exhales air as a function of time is the gold standard for diagnosing, assessing and monitoring COPD. The Forced Expiratory Volume in the first second of maximal expiration after a maximal inspiration ( $FEV_1$ ) is used to grade the severity of COPD and is a marker of disease progression.(138) Figure 7.1 shows the difference in spirometry results between a person with normal lungs and one with COPD. A more detailed explanation of spirometry may be found in Appendix 7.4.

**Figure 7.1 Normal spirometry result versus a COPD result (15)**



- FVC (Forced Vital Capacity): maximum volume of air that can be exhaled during a forced manoeuvre.

- FEV<sub>1</sub> (Forced Expired Volume in one second): volume expired in the first second of maximal expiration after a maximal inspiration.
- FEV<sub>1</sub>/FVC: FEV<sub>1</sub> expressed as a percentage of the FVC, gives a clinically useful index of airflow limitation.
- The ratio FEV<sub>1</sub>/FVC is between 70% and 80% in normal adults; a value less than 70% indicates airflow limitation and the possibility of COPD.

- When a diagnosis of COPD is considered spirometry should be performed. All health professionals managing patients with COPD should have access to spirometry.
- Appropriate training should be provided with regular updates; spirometry services should have relevant quality and control processes.
- Every patient with COPD should have spirometry at least once by a trained person.

### b) Subjective assessment of airflow limitation

The subjective assessment of airflow limitation is characterised by the degree of breathlessness experienced by the patient. Its impact on an individual's life is quantified using the British Medical Research Council (MRC) questionnaire.<sup>(15)</sup> This consists of five statements about perceived breathlessness and is used to describe an individual's experience of functional impairment (Table 7.2).

**Table 7.2 MRC Dyspnoea Scale**

| <b>MRC Dyspnoea Scale</b> |  |
|---------------------------|--|
| Grade 1:                  | Not troubled by breathlessness except on strenuous exercise  |
| Grade 2:                  | Short of breath when hurrying or walking up a slight hill  |
| Grade 3:                  | Walks slower than contemporaries on level ground because of breathlessness, or has to stop for breath when walking at own pace |
| Grade 4:                  | Stops for breath after walking about 100m or after a few minutes on level ground   |
| Grade 5:                  | Too breathless to leave the house or breathless when dressing or undressing  |

Additional investigations which may be of use for some patients or in some situations are shown in Table 7.3. COPD and asthma may be indistinguishable on the basis of history and examination in untreated patients presenting for the first time. It is essential to make the distinction between the two to ensure that the appropriate treatment is instituted (See Appendix 7.5).

**Table 7.3 Additional Investigations**

|  |
|--|
| Additional Investigations  |
| Bronchodilator reversibility testing: <b>To rule out a diagnosis of asthma</b>   |
| Chest X-ray: <b>Seldom diagnostic in COPD but valuable to exclude alternative diagnoses, and identify co morbidities such as cardiac failure</b> |
| Arterial blood gas measurement: <b>Perform in patients with FEV<sub>1</sub> &lt; 50% predicted or with clinical</b>                              |

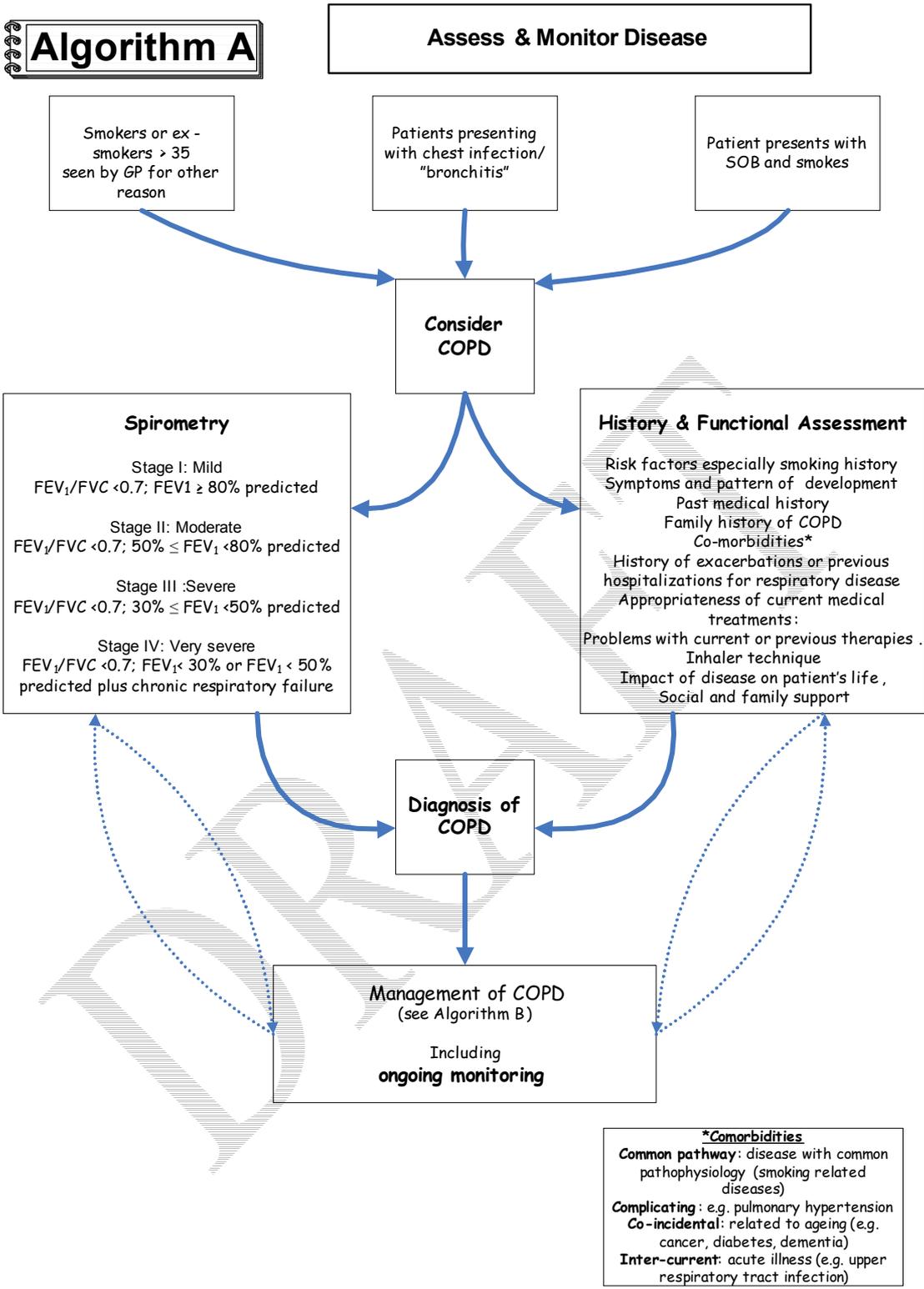
**signs suggestive of respiratory failure or right heart failure**

Pulse Oximetry

Alpha-1 antitrypsin deficiency screening: **Perform when COPD develops in patients under 45 years or with a strong family history of COPD etc (see Chapter 4).**

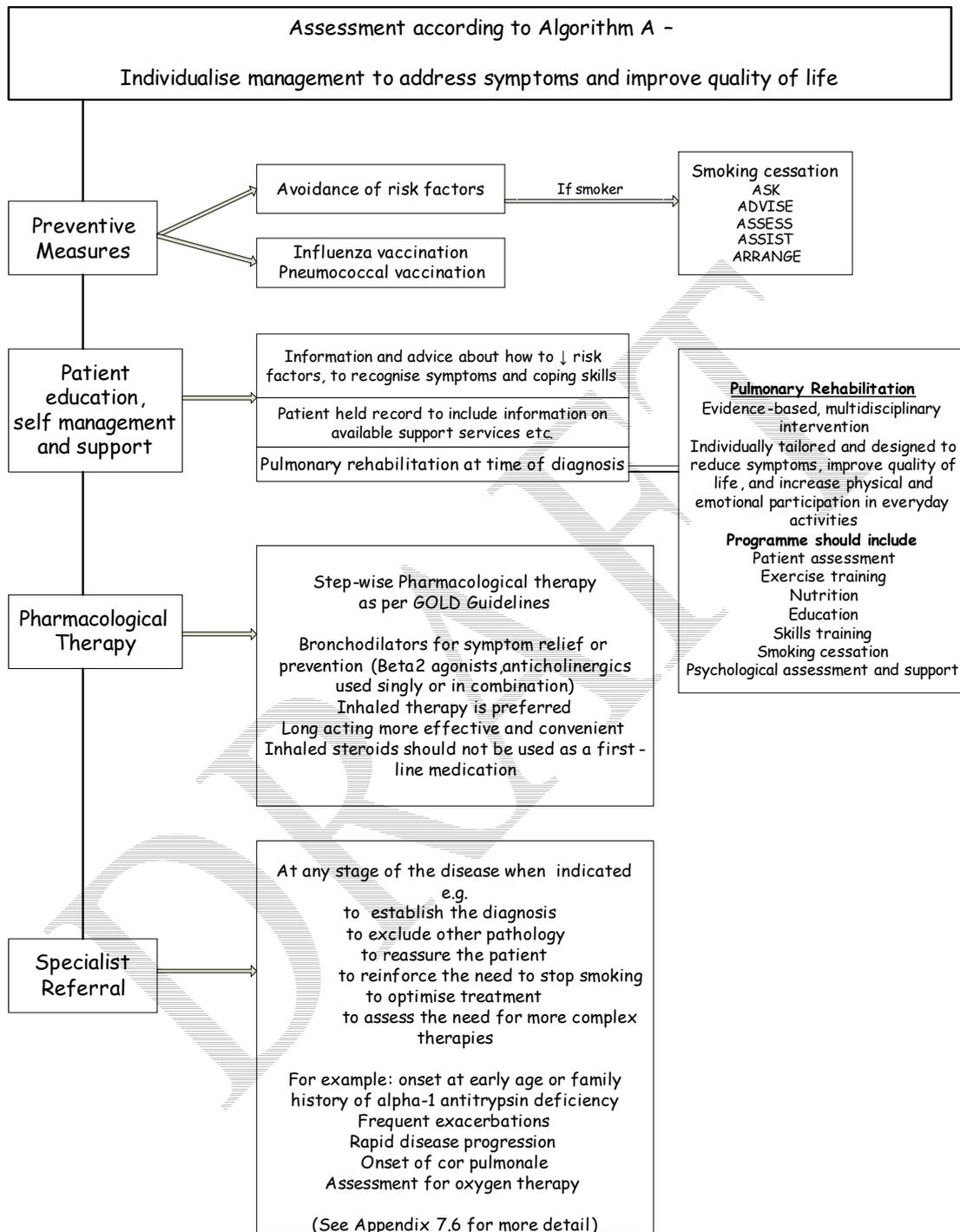
Referral for specialist advice should be considered at any stage of the disease. As evident from Algorithm B, it can be appropriate at all stages of the disease and not solely in the most severely disabled patients (see Appendix 7.6).(137)

DRAFT



# Algorithm B

## Management of Stable COPD



## 7.4 Component 2: Reduce Risk Factors

### Key Points (GOLD)

- Reduction of total personal exposure to tobacco smoke, occupational dusts and chemicals, and indoor and outdoor air pollutants are important goals to prevent the onset and progression of COPD.
- Smoking cessation is the single most effective — and cost effective — intervention in most people to reduce the risk of developing COPD and stop its progression.
- Comprehensive tobacco control policies and programmes with clear, consistent, and repeated non smoking messages should be delivered through every feasible channel.
- Efforts to reduce smoking through public health initiatives should also focus on passive smoking to minimise risks for non smokers.
- Many occupationally induced respiratory disorders can be reduced or controlled through a variety of strategies aimed at reducing the burden of inhaled particles and gases.
- Reducing the risk from indoor and outdoor air pollution is feasible and requires a combination of public policy and protective steps taken by individual patients.

#### 7.4.1 Smoking Cessation

Smoking cessation is the single most effective way to prevent COPD and its progression. Stopping smoking can prevent and delay the development of airflow limitation, reduce its progression, and can have a substantial effect on subsequent mortality.

A five step programme for quitting (Table 7.4) emphasises that tobacco dependence is a chronic disease, that relapse is common and reflects the chronic nature of dependence and addiction.(139-141) Counselling delivered by a health care professional significantly increases quit rates over self-initiated strategies. A brief (3-minute) period of counselling results in smoking cessation rates of 5-10%. At the very least, this should be done for every smoker attending a health professional.

**Table 7.4 Five step programme for smoking cessation**

| <b>Smoking cessation: Five As</b> |  |
|-----------------------------------|--|
| <b>ASK</b>                        | Systematically identify all tobacco users at every visit. Implement a system that ensures that, for EVERY patient at EVERY health service visit, tobacco-use status is queried and documented. |
| <b>ADVISE</b>                     | Strongly urge all tobacco users to quit. In a clear, strong, and personalised manner, urge every tobacco user to quit.   |
| <b>ASSESS</b>                     | Determine willingness to make a quit attempt. Ask every tobacco user if he or she is willing to make a quit attempt at this time (e.g., within the next 30 days).                              |

|                |   |
|----------------|---|
| <b>ASSIST</b>  | Aid the patient in quitting. Help the patient with a quit plan; provide practical counselling; provide intra-treatment social support; help the patient obtain extra-treatment social support; recommend use of approved pharmacotherapy except in special circumstances; provide supplementary materials. (see Appendix 7.7) |
| <b>ARRANGE</b> | Schedule follow-up contact, either in person or via telephone.  |

All smokers—including those who may be at risk for COPD as well as those who already have the disease—should be offered the most intensive smoking cessation intervention feasible.

#### **7.4.2 Risk factors other than smoking**

Other exposures and risk factors including awareness and AAT deficiency are discussed in Chapter 4. Primary prevention is best achieved by the elimination or reduction of exposures to relevant substances. Secondary prevention, achieved through surveillance and early case detection, is also of great importance. (See Appendix 7.7)

### **7.5 Component 3: Management of stable COPD**

#### **Key Points (GOLD)**

- Management of stable COPD should be individualised to address symptoms and improve quality of life.
- Health education plays an important role in smoking cessation and can also play a role in improving skills, ability to cope with illness and health status.
- None of the existing medications for COPD have been shown to modify the long-term decline in lung function that is the hallmark of this disease. Therefore, pharmacotherapy for COPD is used to decrease symptoms and/or complications.
- Bronchodilator medications are central to the symptomatic management of COPD. They are given on an as-needed basis or on a regular basis to prevent or reduce symptoms and exacerbations.
- The principal bronchodilator treatments are beta<sub>2</sub>-agonists, anticholinergics and methylxanthines used singly or in combination.
- Regular treatment with long-acting bronchodilators is more effective and convenient than treatment with short-acting bronchodilators.
- The addition of regular treatment with inhaled glucocorticosteroids to bronchodilator treatment is appropriate for symptomatic COPD patients with an FEV<sub>1</sub> < 50% predicted (Stage III: Severe COPD and Stage IV: Very Severe COPD) and repeated exacerbations.
- Influenza and pneumococcal vaccines are recommended for COPD patients.

- All COPD patients benefit from exercise training programmes, improving with respect to both exercise tolerance and symptoms of dyspnoea and fatigue.
- The long-term administration of oxygen (> 15 hours per day) to patients with chronic respiratory failure has been shown to increase survival.

The overall approach to managing people with stable COPD (as per Algorithm B) should be guided by the following general principles:

- Determine disease severity on an individual basis by taking into account the patient's symptoms, airflow limitation, frequency and severity of exacerbations, complications, respiratory failure, co morbidities, and general health status.
- Implement a stepwise treatment plan that reflects this assessment of disease severity.

### 7.5.1 Pharmacological Management

Pharmacologic therapy is used to:

- prevent and control symptoms
- reduce the frequency and severity of exacerbations
- improve health status
- improve exercise tolerance

Since COPD is usually progressive, recommendations for the pharmacological treatment of COPD reflect the following principles:

- Treatment should be cumulative with more medications required as the disease state worsens
- Regular treatment needs to be maintained at the same level for long periods unless significant side effects occur or the disease worsens
- Individuals differ in their response to treatment; careful monitoring is needed over an appropriate period to ensure that the specific aim of introducing a therapy has been met without an unacceptable cost to the patient.

#### Key points on Bronchodilators

- **Bronchodilators are central to symptom management of COPD**
- **Inhaled therapy is preferred**
- **Use “as required” to relieve intermittent or worsening symptoms and on a regular basis to prevent or reduce persistent symptoms**
- **The choice depends on the availability of medications and each patient's individual response in terms of both symptom relief and side effects**
- **Regular treatment with long-acting inhaled bronchodilators is more effective and convenient than treatment with short-acting bronchodilators**

- **Training and regular review of inhaler technique is essential**
- **Combining bronchodilators may improve efficacy and decrease the risk of side effects compared to increasing the dose of a single bronchodilator**
- **Regular treatment with inhaled glucocorticosteroids is only appropriate for patients with an FEV<sub>1</sub> <50% predicted and repeated exacerbations (e.g. three in the last three years)**
- **Long-term treatment with oral glucocorticosteroids is not recommended in COPD.**

More detail on the medications commonly used in treating COPD and the various delivery systems may be found in Appendix 7.8.

Pharmacologic therapy by disease severity is summarised in Figure 7.2.(15)

**Figure 7.2 Recommended therapy according to stage of COPD**

| I: Mild   | II: Moderate  | III: Severe  | IV: Very severe   |
|---|---|--|---|
| Active reduction of risk factors; relevant immunisation |   |  | →   |
| Add short-acting bronchodilator (when needed)           |   |  | →   |
|   | Add regular treatment with one or more long-acting bronchodilators (when needed); add *rehabilitation |  |   |
|   |   | Add inhaled glucocorticosteroids if repeated exacerbations |   |
|   |   |  | Add long term oxygen therapy if chronic respiratory failure<br>Consider surgical treatments |

\*Ideally rehabilitation should be offered at time of diagnosis which soon be as early as possible in disease severity

#### **Other pharmacological treatments**

- Influenza and pneumococcal vaccination as per National Immunisation Guidelines.(142)
- Alpha -1 antitrypsin therapy replacement therapy for appropriate patients
- Antibiotics: Not recommended except for the treatment of infectious exacerbations and other bacterial infections
- Others:
  - The regular use of antitussives is not recommended in stable COPD
  - The use of mucolytic agents is not recommended at present.

#### **7.5.2 Non-Pharmacological Management**

Algorithm B sets out a management plan individualised to address symptoms and improve quality of life. It includes the non-pharmacological aspects of management of patients with COPD.

#### **a) Patient education, self-management and support**

- Patient education can play a role in improving skills, ability to cope with illness and health status. Patient education regarding smoking cessation has the greatest capacity to influence the natural history of COPD.
- Ideally, educational messages should be incorporated into all aspects of care and in all settings, from the first assessment and continuing with each follow-up visit for COPD.
- Topics should include information about the nature of COPD, advice about reducing risk factors, recognising symptoms, coping skills including specific information on treatment options as disease severity increases. The intensity and content of these educational messages should vary depending on the severity of the patient's disease.
- Each patient should have a patient held card, to facilitate ease of sharing key information with relevant settings and professionals which has information on available support services.
- Each patient should have a self management plan with advice on how to prevent exacerbations and actions in the event of one occurring.

#### **b) Pulmonary rehabilitation**

The principal goals of pulmonary rehabilitation are to reduce symptoms, improve quality of life, and increase physical and emotional participation in everyday activities.(15)

To accomplish these goals, pulmonary rehabilitation tackles a range of non-pulmonary problems that are not adequately addressed by medical therapy for COPD. Such problems include exercise de-conditioning, relative social isolation, altered mood states (especially depression), muscle wasting, and weight loss. These problems have complex inter-relationships and improvement in any one of these interlinked processes can interrupt the "vicious circle" in COPD so that positive gains occur in all aspects of the illness. GOLD refers to the comprehensive statement on pulmonary rehabilitation prepared by the American Thoracic Society and the European Respiratory Society (ATS & ERS) which includes its definition (Table 7.5).(143).

#### **Table 7.5 ATS and ERS definition of Pulmonary Rehabilitation**

## **Pulmonary Rehabilitation**

- Pulmonary rehabilitation is an evidence-based, multidisciplinary, and comprehensive intervention for patients with chronic respiratory diseases who are symptomatic and often have decreased daily life activities.
- Integrated into the individualised treatment of the patient, pulmonary rehabilitation is designed to reduce symptoms, optimise functional status, increase participation, and reduce health-care costs through stabilising or reversing systemic manifestations of the disease.
- Comprehensive pulmonary rehabilitation programmes include patient assessment, exercise training, education, nutritional intervention, skills training, smoking cessation and psychosocial support.

The American Association of Cardiovascular and Pulmonary Rehabilitation (AACVPR) and the American College of Chest Physicians (ACCP) published joint evidence based clinical practice guidelines for pulmonary rehabilitation.(144). A referral and resources page may be accessed via the internet<sup>9</sup> while Appendix 7.9 gives additional information. The minimum length of an effective rehabilitation program is six weeks; the longer the programme continues the more effective the results.(145-147)

### **c) Controlled Oxygen Therapy**

As COPD progresses patients may become hypoxaemic. Many patients tolerate mild hypoxaemia well, but once the resting PaO<sub>2</sub> falls < 8kPa patients begin to develop signs of cor pulmonale, principally peripheral oedema.(137) Some patients with COPD become transiently hypoxaemic on exercise and oxygen is used to improve exercise capacity and reduce disability in these individuals. Oxygen is also used to provide symptomatic relief of breathlessness.

Thus in stable COPD oxygen can be administered for long periods during the day and night (long term oxygen therapy (LTOT)), or as ambulatory oxygen (either as part of LTOT or on its own to facilitate exercise). LTOT should ideally be administered continuously (i.e. 24hrs/day), as improvement in survival is only seen above a minimum usage of 15hours/day.(15, 69)

Oxygen is one of the principal non-pharmacologic treatments for patients with Stage IV: Very Severe COPD. Its main aim during an exacerbation is to prevent life-threatening hypoxaemia. It is used to increase the baseline PaO<sub>2</sub> to at least 8.0 kPa at sea level and rest, and/or produce an SaO<sub>2</sub> at least 90% ( 88-92% is the currently accepted practice in Ireland).

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<sup>9</sup> <http://www.aacvpr.org/dmtf/pulmonaryspecific.cfm>

Additional details on this very important topic, including flow chart for oxygen prescription, ambulatory oxygen therapy, and oxygen therapy during transportation to hospital are included in Appendix 7.10.

#### **d) Surgical treatment**

Surgical treatment including bullectomy, insertion of stents, and lung transplantation may be considered in carefully selected patients.

## **7.6 Component 4 Manage Exacerbations**

### **Key Points (GOLD)**

- The most common cause is infection but other causes such as air pollution may play a role
- Inhaled bronchodilators and oral glucocorticosteroids are effective treatments
- COPD exacerbations with clinical signs of infection may benefit from antibiotic treatment
- Non invasive mechanical ventilation in exacerbations associated with respiratory failure improves respiratory acidosis, increases pH, decreases the need for endotracheal intubation, and reduces PaCO<sub>2</sub>, respiratory rate, severity of breathlessness, the length of hospital stay, and mortality
- Medications and education to help prevent future exacerbations should be considered as part of follow-up, as exacerbations affect the quality of life and patients with COPD.

Definition: An acute exacerbation of COPD (AECOPD) is a change in the patient's baseline dyspnoea, cough, and/or sputum that is beyond normal day-to-day variations. It is acute in onset and may warrant a change in regular medication in a patient with underlying COPD.

The management of AECOPD is set out in Algorithms C and D and figure 7.3.

#### **7.6.1 Prevention**

It is possible to reduce both frequency and severity of exacerbations. In previous sections reduction in exposure to risk factors and the value of patient education and support were discussed. The elements of prevention listed below are of vital importance in both the prevention and /or amelioration of exacerbations.

- Patient education
- Smoking cessation and Nicotine Replacement Therapy (NRT)
- Vaccination: influenza and pneumococcal

- Pulmonary rehabilitation can be beneficial at all stages of disease including for patients recovering from an exacerbation

### 7.6.2 Diagnosis and assessment of severity

Assessment of the severity of an exacerbation is based on the patient's medical history before the exacerbation, pre-existing co morbidities, symptoms, physical examination, arterial blood gas measurements and other laboratory tests. Specific information is required on the frequency and severity of attacks of breathlessness and cough, sputum volume and colour, and limitation of daily activities. A stepwise approach with four components forms the diagnostic assessment and is summarised in Table 7.6 below.(148)

**Table 7.6 Diagnostic Assessment**

| <b>Four Steps</b>  |
|--|
| <ul style="list-style-type: none"> <li>• An appropriate medical history which identifies one or more of the three cardinal symptoms: increased shortness of breath, increased sputum volume and increased sputum purulence.</li> <li>• A physical examination to identify the principal respiratory signs, cardiovascular signs and general signs</li> <li>• The recognition of clinical conditions that are often associated with COPD</li> <li>• Additional diagnostic procedures may be of use: such as arterial blood gas analysis, chest X-ray, Gram stain of purulent sputum, ECG and pulse oximetry.</li> </ul> |

### 7.6.3 Pharmacological Management

The 'ABC approach to the pharmacological management', as recommended by Rodriguez, reflects the three classes of drugs (Antibiotics, Bronchodilators and Corticosteroids) commonly used for exacerbations of COPD (Table 7.7 and Algorithm C).(148)

**Table 7.7 ABC approach to the pharmacological management**

|  |
|--|
| <p><b>Antibiotics:</b> <i>Oral antibiotics if sputum is purulent</i></p> <p><b>Bronchodilators:</b> <i>Increase frequency of bronchodilator therapy; consider changing to nebulised therapy</i></p> <p><b>Corticosteroids:</b> <i>Prednisolone 30 mg daily for 7-14 days</i></p> |
|--|

In the management of an exacerbation at home; a stepwise therapeutic approach is summarised in the flow chart below (Figure 7.3).(148) Information on pharmacological management is provided in the section on the management of stable COPD.

#### a) Antibiotics

The infectious agents in COPD exacerbations can be viral or bacterial. The choice of antibiotic should be guided by local antibiotics guidelines. Antibiotics should be given to patients:

- with the following three cardinal symptoms: increased dyspnoea, increased sputum volume, and increased sputum purulence
- with increased sputum purulence and one other cardinal symptom
- who require mechanical ventilation (invasive or non invasive).

#### **b) Bronchodilator therapy**

- Increase dose and/or frequency of existing short-acting bronchodilator therapy, preferably with beta<sub>2</sub>-agonists
- Short-acting inhaled beta<sub>2</sub>-agonists are usually the preferred bronchodilators for treatment of exacerbations
- Consider use of spacers or air driven nebulisers to deliver bronchodilators
- Patients admitted to hospital should be treated with nebulised bronchodilators
- If a prompt response does not occur, the addition of an anticholinergic is recommended, even though evidence concerning the effectiveness of this combination is controversial.

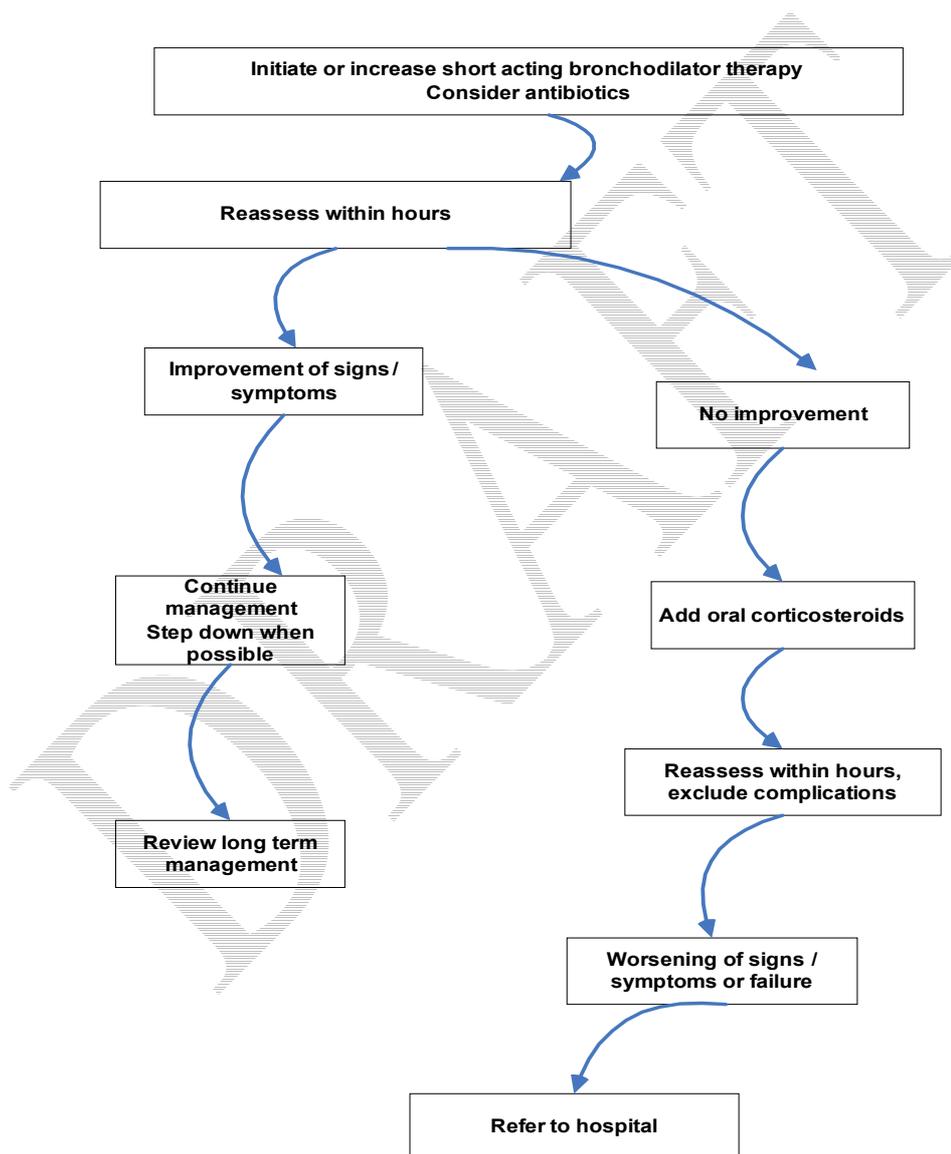
#### **c) Corticosteroids**

- In the absence of significant contraindications, oral corticosteroids should be considered in patients managed in the community who have an exacerbation with a significant increase in breathlessness which interferes with daily activities.
- In the absence of significant contraindications oral corticosteroids should be used, in conjunction with other therapies, in all patients admitted to hospital with an exacerbation of COPD.
- Long term use of systemic corticosteroids is not recommended.
- Regular treatment with inhaled corticosteroids is only appropriate for patients with an FEV<sub>1</sub> <50% predicted and repeated exacerbations (for example, three in last three years). An inhaled corticosteroid combined with a long-acting beta<sub>2</sub>-agonist is more effective than the individual components in reducing exacerbations and improving lung function and health status.
- Oral or intravenous steroids are recommended as an addition to other therapies in the hospital management of exacerbations of COPD.
- Thirty to 40 mg of oral prednisolone daily for 7 to 10 days is effective and safe. Prolonged treatment does not result in greater efficacy and increases the risk of side effects (e.g., hyperglycaemia, muscle atrophy)
- Osteoporosis prophylaxis should be considered in patients requiring frequent courses of oral corticosteroids.

#### d) Adjunct therapies

The ABC approach to the management of COPD is focused on the respiratory symptoms. At all times it is essential to monitor fluid balance and nutrition, to consider subcutaneous heparin, to identify and treat associated conditions (heart failure, arrhythmias), to provide smoking cessation support including nicotine replacement and to closely monitor the patient's condition (Algorithm C).

**Figure 7.3 Stepwise therapeutic approach to management of an exacerbation in the community.(148)**



#### 7.6.4 Non-pharmacological Management

##### a) Controlled Oxygen therapy

Aspects of oxygen therapy are dealt with in section 7.5.2 and appendix 7.10..

## b) Ventilatory support

- The primary objectives of mechanical ventilatory support in patients with COPD exacerbations are to decrease mortality and morbidity and to relieve symptoms.
- Ventilatory support includes non-invasive intermittent ventilation (NIV), using either negative or positive pressure devices, which does not require intubation and invasive (conventional) mechanical ventilation by oro-tracheal tube or tracheostomy.
- NIV is usually delivered via a mask that covers the nose, but occasionally a full face mask covering the nose and the mouth is required.
- NIV used for the treatment of respiratory failure occurring during exacerbations of COPD has many advantages over intubation and ventilation and can be used outside intensive care units.

**Table 7.8 Aspect of NIV based on BTS/NICE guidelines (137)**

|   |
|---|
| NIV from BTS/NICE   |
| <ul style="list-style-type: none"><li>• <b>NIV is the treatment of choice for persistent hypercapnic ventilatory failure during exacerbations despite optimal medical therapy.</b></li><li>• <b>NIV should be delivered in a dedicated setting with staff who have been trained in its application, are experienced in its use and who are aware of its limitations.</b></li><li>• <b>When patients are started on NIV there should be a clear plan covering what to do in the event of deterioration and ceilings of therapy should be agreed.</b></li></ul> |

**Any hospital admitting acute medical emergencies should have access to NIV**

**Indications for invasive mechanical ventilation:** Although non-invasive ventilation is the initial treatment of choice for respiratory failure during exacerbations of COPD, some patients do not respond adequately to NIV and require intubation and ventilation (See Appendix 7.11). Other patients have multiple organ system impairment or reduced levels of consciousness and in these circumstances care in an intensive therapy unit (ITU) may be the appropriate first line management option. In the past there has often been a reluctance to intubate patients with COPD or admit them to ITUs because of concerns about weaning and long term outcomes.(137)

Patients with several of the previous indications for invasive mechanical ventilation are now being successfully treated with NIV. The GOLD indications for initiating invasive mechanical ventilation during exacerbations of COPD include:

- Unable to tolerate NIV or NIV failure
- Severe dyspnoea with use of accessory muscles and paradoxical abdominal motion
- Respiratory frequency > 35 breaths per minute

- Life-threatening hypoxemia
- Severe acidosis (pH < 7.25) and/or hypercapnia (PaCO<sub>2</sub> > 8.0 kPa, 60 mm Hg)
- Respiratory arrest
- Somnolence, impaired mental status
- Cardiovascular complications (hypotension, shock)
- Other complications (metabolic abnormalities, sepsis, pneumonia, pulmonary embolism, barotrauma, massive pleural effusion).

The use of invasive ventilation in patients with end-stage COPD is influenced by the likely reversibility of the precipitating event, the patient's wishes and the availability of intensive care facilities. When possible, a clear statement of the patient's own treatment wishes — an advance directive or “living will”— makes these difficult decisions easier to resolve.

- Neither age nor FEV<sub>1</sub> should be used in isolation when assessing suitability for intubation and ventilation during an exacerbation of COPD. Other factors to consider are functional status, BMI, requirement for oxygen when stable, co-morbidities and previous admissions to intensive care units.
- NIV should be considered for patients who are slow to wean from invasive ventilation.

#### **7.6.5 Monitoring recovery from an exacerbation (BTS)(137)**

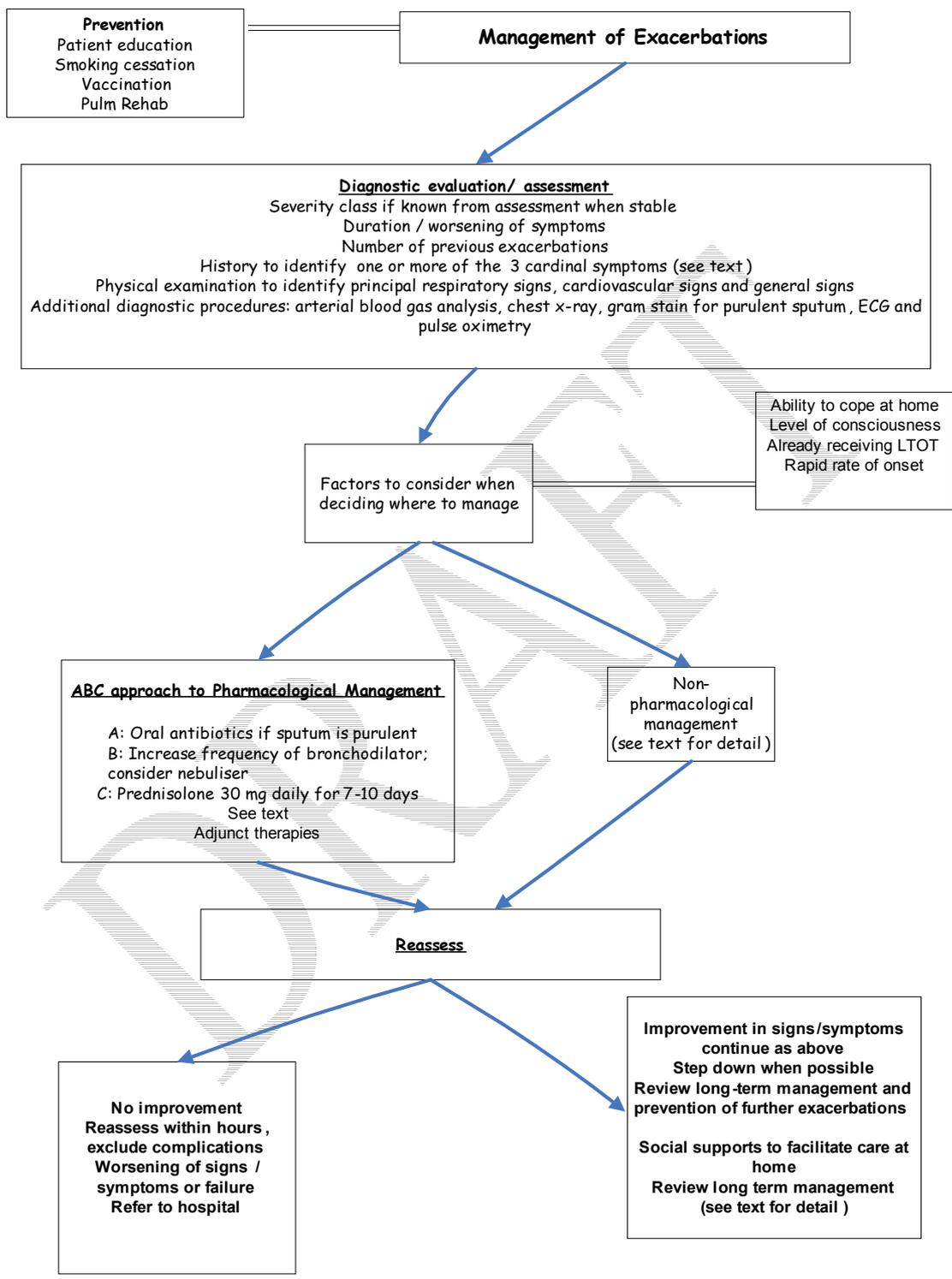
- Patients' recovery should be monitored by regular clinical assessment of their symptoms and observation of their functional capacity
- Pulse oximetry should be used to monitor the recovery of patients with non hypercapnic, non-acidotic respiratory failure
- Intermittent arterial blood gas measurements should be used to monitor the recovery of patients with respiratory failure who are hypercapnic or acidotic, until they are stable.

#### **7.6.6 Treatment Location**

Most patients with an exacerbation of COPD can be managed at home but some will need access to specialist assessment / opinion either in home or in hospital, assessment in a MAU, or in-patient admission.(137) (See Algorithm D). This may be because of the severity of the exacerbation, the need for therapies that are not available to that patient at home (such as oxygen or nebulised bronchodilators), or the need for specialist interventions such as non-invasive ventilation. The following factors should be taken into consideration when deciding where to manage a patient with an exacerbation of COPD (Algorithm C).

- Ability to cope at home
- Level of consciousness
- Already receiving long term oxygen therapy
- Rapid rate of onset of exacerbation.

# Algorithm C Management of AECOPD



## 7.6.7 Hospital Management

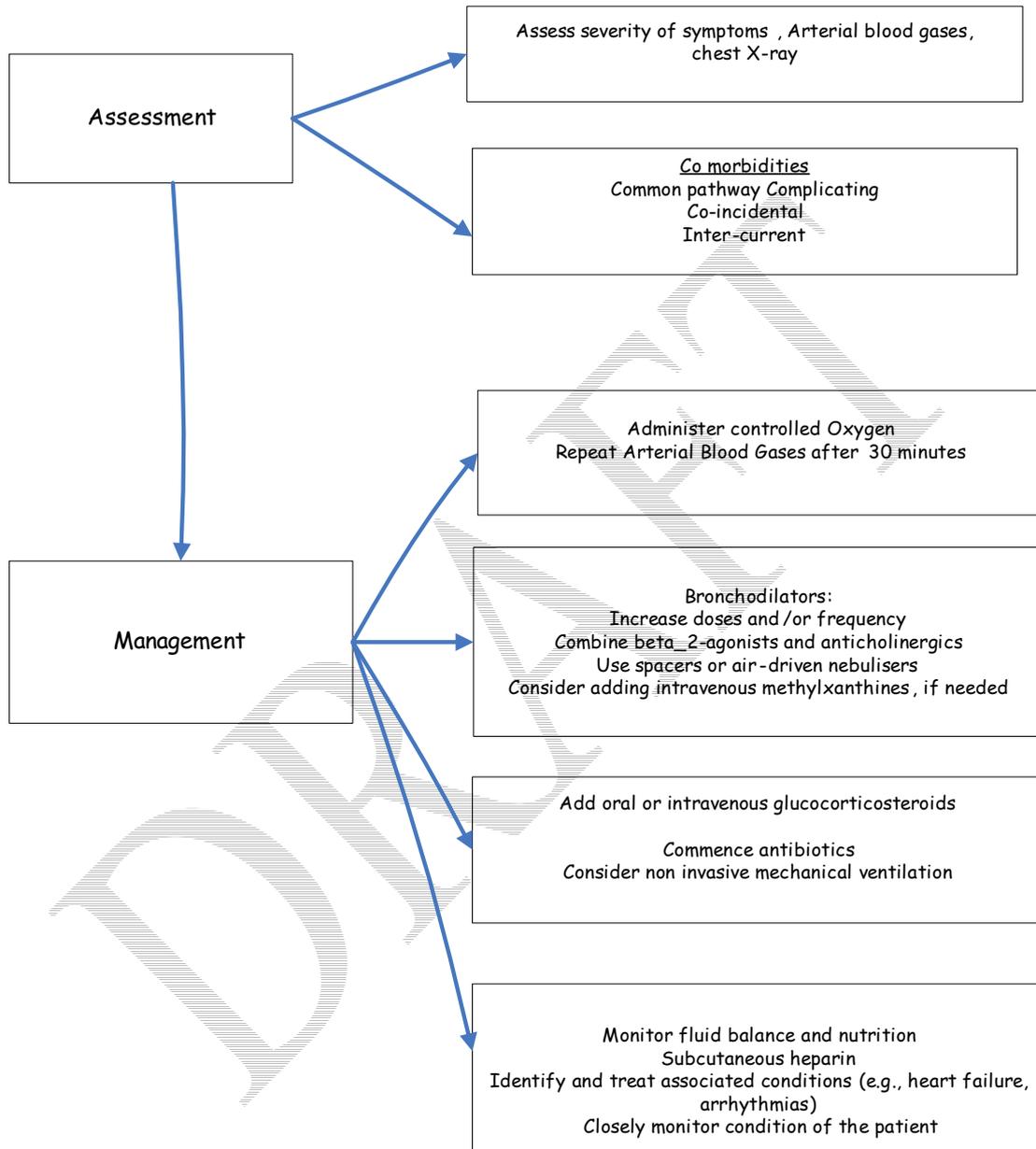
Exacerbations may be managed in the home or in the hospital, depending on the factors described above. Generally, with the exception of invasive or non-invasive mechanical ventilation, many of the therapies are suitable for delivery to patients at home. There are a number of ways in which care can be delivered to patients with exacerbations of COPD. Appendix 7.12 provides detail on alternative care options including rapid assessment units, early discharge schemes and hospital-at-home models of care.

Algorithm D below sets out a suggested approach to the management of severe but not life-threatening exacerbations of COPD in an Emergency Department or Medical Assessment Unit.

DRAFT

## Algorithm D

Management of severe but not life-threatening exacerbations of COPD in Emergency Department / Medical Assessment Unit



Admission to an Intensive Care Unit, a High Dependency Unit or to a specialised NIV unit should be considered for patients with an exacerbation of COPD who have the following:

- Severe dyspnoea that responds inadequately to initial emergency therapy
- Changes in mental status (confusion, lethargy, coma)
- Persistent or worsening hypoxemia ( $\text{PaO}_2 < 5.3 \text{ kPa}$ , 40 mmHg), and/or severe/worsening hypercapnia ( $\text{PaCO}_2 > 8.0 \text{ kPa}$ , 60 mmHg), and/or severe/worsening respiratory acidosis ( $\text{pH} < 7.25$ ) despite supplemental oxygen and non invasive ventilation

- Need for invasive mechanical ventilation
- Haemodynamic instability—need for vasopressors

### 7.6.8 Discharge and Follow-up

Advanced discharge planning will reduce the risk of re-admission and reduce unnecessary hospital bed occupancy. Spirometry close to the time of discharge will give a result close to the patient's normal functional state.

#### Discharge Criteria

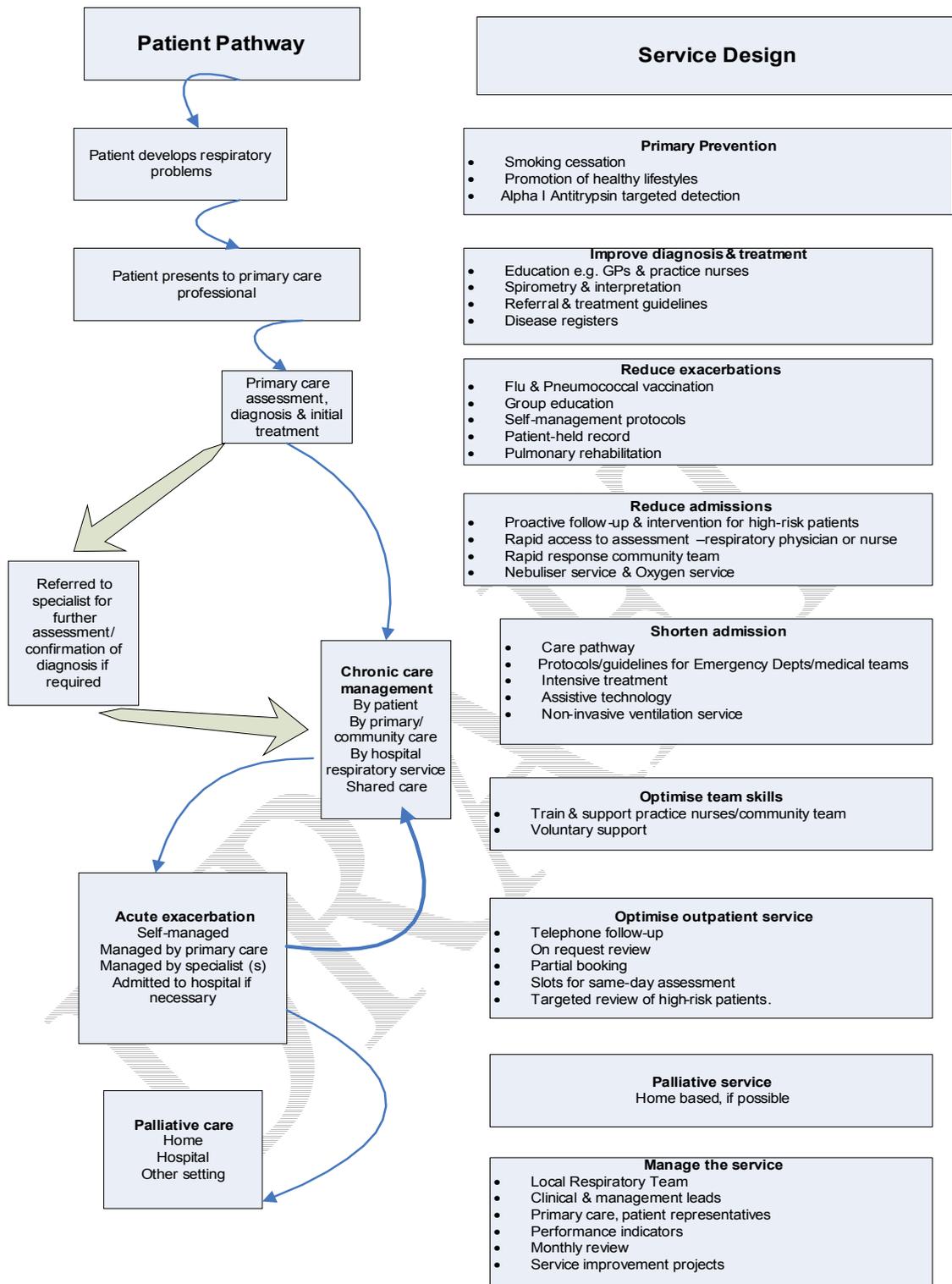
- Patient is medically stable
  - Inhaled beta<sub>2</sub>-agonist therapy is required ≤ every 4 hrs
  - Patient, if previously ambulatory, is able to walk across room
  - Patient is able to eat and sleep without frequent awakening by dyspnoea
  - Patient has been clinically stable for 12-24 hrs
  - Arterial blood gases have been stable for 12-24 hrs
- Patient or carer is fully informed and understands treatment
- Patient and care confident that patient can manage at home
- Discharge plan is documented
- Follow-up and home care arrangements have been completed (e.g., visiting nurse, oxygen delivery, meal provisions).

Similarly, discharge planning should be carried out for those managed by specialist services in the community. Care should be taken to ensure that patients who are cared for in the community during an exacerbation – thus avoiding hospital admission – can still access the same specialist follow-up services, e.g. referral for pulmonary rehabilitation. For this to occur there must be close integration between community and hospital-based services.

## 7.7 Conclusion

The evidence based guidelines outlined in this chapter are based on the internationally developed and recognised GOLD guidelines. These guidelines can inform the delivery of a pathway of care for patients as shown in Figure 7.4, which will provide patient centred integrated care in the appropriate setting at the appropriate time.

### Figure 7.4 Generic Patient Pathway for COPD (adapted)(149)



## Chapter 8 Strategic Approach

### Key Points

- The HSE is committed to providing integrated evidence based care, in appropriate settings, using the chronic disease management model as part of the population health approach where relevant.
- The vision for respiratory health is to reduce the growing burden of respiratory disease, including COPD, by the development of a continuum of disease prevention and care interventions which are matched to level of health care needs of all patients.
- The approach required for service structures for COPD is similar to that needed for respiratory diseases in general.
- The approach proposed will enable delivery of the goals to:
  - Prevent the development and progression of COPD
  - Ensure timely access to comprehensive and integrated services in appropriate settings
  - Empower patients & carers to actively participate in the management of their condition
  - Enable health care workers to deliver an evidence based service.
- The comprehensive cohesive approach to respiratory health proposed here will achieve for respiratory health a reduction in morbidity and mortality, as was achieved for cardio-vascular disease over the past two decades

### 8.1 Introduction

*“Integrated care is a concept bringing together inputs, delivery, management and organization of services related to diagnosis, treatment, care, rehabilitation and health promotion. Integration is a means to improve services in relation to access, quality, user satisfaction and efficiency.”(150)*

The HSE is committed to the development and implementation of a fully integrated health system which will deliver a better quality of care for patients in a more cost effective way.(25)

Continuity of care and integrated care are not synonymous. Continuity of care emphasises the patients’ experience and journey through the system of health services. It refers to longitudinal continuity, continuity across the secondary/primary care interface and continuity of information.(151) Integrated care refers not only to the patients’ perspective but also to the technological, managerial and economic implications of service integration.

This chapter, which outlines the goals, objectives and recommendations for this respiratory strategy takes cognisance of key documents produced by both the DOHC and HSE over the past number of years.(21, 152) These were previously highlighted in the policy context of Chapter 1 (Introduction). The Primary Care Strategy recommended that primary care settings, based on the multi-disciplinary team, should be at the centre of health care delivery.(152)

The HSE's Transformation Programme identified improving the health of the population as a key priority. This includes the prevention and management of chronic illness of which COPD is a major contributor. All of the six priorities of the Transformation Programme's are of particular relevance to this strategy:

- Develop integrated services across all stages of the care journey
- Configure Primary, Community & Continuing Care services so that they deliver optimal and cost effective results
- Configure hospital services to deliver optimal and cost effective results
- Implement a model for the prevention and management of chronic illness
- Implement standards based performance measurement and management
- Ensure all staff engage in transforming health and social care in Ireland.

The policy framework on chronic diseases,(24) the HSE's document on Chronic Illness Framework(24) and the HSE's Population Health Strategy(153) require action on the determinants of health and self management support, as well as delivering high quality integrated health care services, which ensures that those with chronic illness can return to the least complex and appropriate level of care. The goals developed are in line with the generic goals for those with chronic disease (Appendix 8).

Outlined here is an approach for the provision of quality integrated health care, for those with or at risk of respiratory diseases. As health is influenced by many factors outside the health sector, the achievement of respiratory health involves working in partnership with many organisations both within and outside the health sector. Such partnerships are in keeping with a population health approach.

## **8.2 Vision, Mission and Principles**

### **Vision**

To reduce the growing burden of COPD by the development of a continuum of disease prevention and integrated care interventions matched to level of health care needs of all patients.(154)

### **Mission**

- Prevent and limit the progression of COPD, through prevention, early detection, treatment and effective management
- Reduce variations in care
- Reduce preventable hospital admissions.

### **Principles**

- Adopt a Chronic Disease Model
- Adopt a Population Health approach
- Prioritise health promotion and disease prevention
- Provide the most effective care
- Achieve person centred care and optimise self-management
- Facilitate co-ordinated and integrated multidisciplinary care across settings, services and sectors
- Evaluate and monitor progress to achieve significant and sustainable health gain
- Support and encourage the application of evidenced-based practice
- Focus on issues of equity in the particular context for many with or at risk of COPD
- Acknowledge carers and families affected by COPD as part of the broader experience of this condition
- Acknowledge that many chronic diseases share risk factors both causative and additive e.g. smoking etc.

### **8.3 Goals**

To achieve the vision outlined above, a national approach for the delivery of respiratory care, including COPD, is required. This national approach together with an implementation structure will be the catalyst to attaining this vision.

The national approach and implementation structure are outlined under Goal 1 followed by four further goals, each with objectives and recommendations, which are more specific and process orientated. The implementation of Goal 1 will ensure achievement of Goals 2-5.

#### **Implementation – Goal 1**

An organisational framework with five levels is recommended with key players at national, regional level (currently hospital network<sup>10</sup>) and local levels. As goals 2-5 for COPD are equally relevant for all respiratory diseases the structure proposed here is valid for respiratory health in general and not just COPD. For each of the levels there are key roles and responsibilities in ensuring that Goals 2-5 are delivered in a planned cohesive manner.

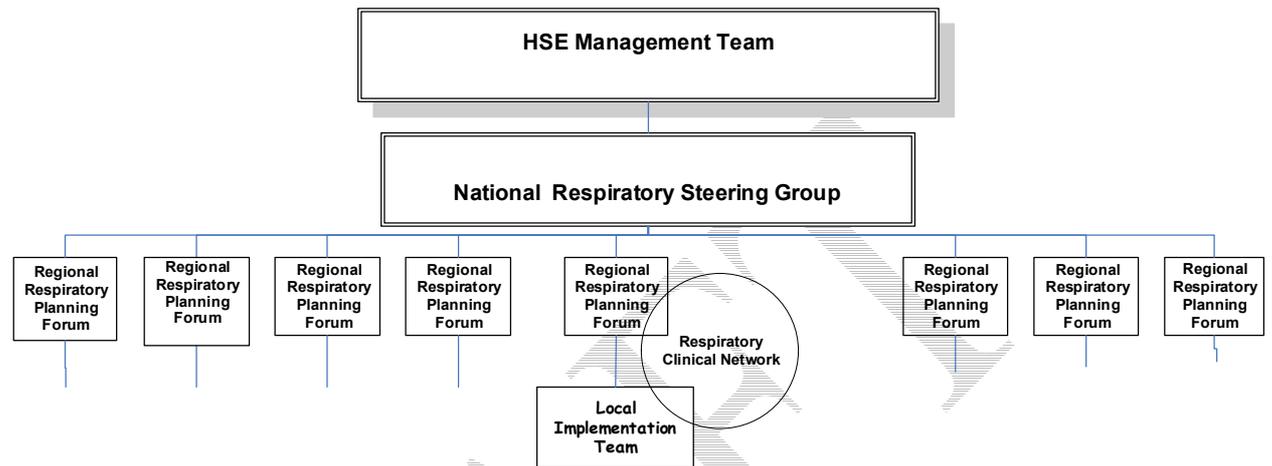
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<sup>10</sup> Note: pending any re-configuring of services, the term hospital network level will be used

The following goals while using the term COPD are equally applicable to respiratory disease in general.

**Recommendation:** The implementation framework proposed below should be established for respiratory disease as a group rather than specifically for COPD.

**Figure 8.1 Implementation Framework Respiratory Health Services**



**HSE Management Team**

The Management Team of HSE has ultimate responsibility to ensure the implementation of this strategy.

**Recommendation:** The development of COPD services at national level should be prioritised and should be reflected in the HSE national service plan.

**National Respiratory Steering Group**

**Recommendation:** A National Respiratory Steering Group (which will include COPD) should be established under the HSE Management Team. *Target- September 2008.*

**Membership:** Representatives with expertise and responsibility for respiratory health (including COPD) from across the spectrum of health services and settings.

**Roles and Responsibilities:** To provide high level direction and guidance on priorities for national respiratory service development and delivery including a National Plan for respiratory health services (see appendix).

**Recommendation:** The National Steering Group should be supported by a dedicated National Office/Secretariat (*Target- January 2009*).

Roles and Responsibilities of National Office/Secretariat: To be a centre/repository for respiratory health (including COPD) incorporating training, research and health information materials which will:

- support the work of the National Steering group
- support people affected with COPD through development of a nationwide network of local COPD support groups
- help people to understand their condition by providing comprehensive and clear information in all media formats
- work for positive change in respiratory health by advocating, raising awareness and forming international links
- provide a focus for respiratory disease including COPD within the wider context of health and chronic diseases in Ireland.

|   |
|---|
| <b>Regional Respiratory Planning Fora</b> |
|---|

|   |
|---|
| <b>Recommendation:</b> Regional Respiratory (including COPD) Planning Fora should be established at HSE Network level ( <i>Target – September 2008</i> ). |
|---|

Membership: Representatives with expertise and with responsibility for respiratory health including COPD across the spectrum of HSE services and settings in the area covered by the Network, including clinical respiratory (COPD) networks (see below). It should link with other relevant non-health services, with patient representatives and with respiratory (COPD) interest groups in their area.

Roles and Responsibilities: To provide leadership, direction and a regional plan for their geographic area on the development, implementation and evaluation of regional respiratory (including COPD) plans, based on regional needs and in line with plan of the National Steering group.

|  |
|--|
| <b>Local Implementation Teams (LITs)</b> |
|--|

|  |
|--|
| <b>Recommendation:</b> The remit, membership and resources of current Local Implementation Teams should be expanded to implement the national respiratory plans at local level, following on regional needs assessment. ( <i>Target - September 2008</i> ) |
|--|

(Alternatively, separate LITs could be established for chronic disease care starting with COPD to implement the national plans at local level, following on regional needs assessment). (*Target - September 2008*)

Membership: As per existing LITs with the addition of appropriate support staff.

Roles and Responsibilities: To implement the National plan based at local level following regional needs assessment.

### **Respiratory Clinical Networks**

**Recommendation:** Clinical Networks for respiratory (including COPD) care, defined as linked groups of health professionals and organisations from across care settings, working in a co-ordinated manner to ensure the equitable provision of high quality, clinically effective services throughout the country, should be identified and organised with at least one per HSE Network (*Target January 2009*)

Membership: Clinical representatives from relevant health professionals from across care services and settings.

Roles & Responsibilities:

- Respiratory clinical networks (including COPD) in the primary and acute care settings should be mapped out and should be sufficiently flexible to allow specialist respiratory support for both professionals and patients regardless of health care setting. This specialist respiratory support should include expert advice, rapid assessment, management and appropriate follow-up.
- Establish working arrangements between Primary care and other settings and across disciplines to develop management and referral protocols for patients with respiratory disease (including COPD) within the region. Respiratory (including COPD) programmes should be supported by networks and clinical pathways that cut across the traditional boundaries of healthcare delivery.
- Ensure that all of the respiratory disciplines in a region can work in a co-ordinated /linked manner such that no one person/discipline works in isolation and the service they provide is seamless.

The implementation approach recommended above will help achieve the required "shift" in the way care is delivered away from a reactive "one size fits all" approach, often delivered in a hospital setting, towards a community based, responsive, adaptable, flexible service.(155)

### **Goals (2-5)**

The four goals which follow together with their objectives and recommendations have been developed with COPD as the focus. However they are equally pertinent to respiratory diseases as a group. The delivery of those marked with an asterisk (\*) will be greatly facilitated by the implementation of the structural framework recommended in Goal 1. (Appendix 11 has target examples for the various objectives).

The four goals are to:

- Prevent the development and progression of respiratory disease
- Ensure timely access to comprehensive and integrated services in appropriate settings
- Empower patients and carers to actively participate in the management of their condition
- Enable health care workers to deliver an evidence-based service.

|               |  |
|---------------|--|
| <b>Goal 2</b> | <b>Prevent the development and progression of COPD</b>   |
| Objectives    | <ol style="list-style-type: none"> <li>1. Increase population and individual awareness of COPD.</li> <li>2. Strengthen health promotion efforts relevant to COPD.</li> <li>3. Provide patients and carers with comprehensive, user-friendly information at the time of diagnosis and throughout course of illness.</li> <li>4. Advocate for respiratory health where people live, work and play</li> </ol> |

**Objective 1: Increase population and individual awareness of COPD**

**Recommendations**

- 1 \*The National Steering Group should work with national and local organisations while drawing on international experience to raise public awareness, knowledge and understanding of COPD and its causes in the workplace, in the home and environment to:
  - Develop and increase public awareness and knowledge of COPD through specific initiatives and communication strategies
  - Use opportunities to engage with stakeholders, including employers and statutory/regulatory bodies, to address factors linked with COPD
  - Focus on opportunities to promote healthy respiratory environments.

**Objective 2: Strengthen health promotion efforts relevant to COPD.**

**Recommendations**

- 1 \*Effective measures to prevent initiation of smoking and to support smoking cessation should be an integral part of all relevant Government policies.
- 2 \*As smoking is an addiction and a chronic relapsing disorder, all patients with COPD who continue to smoke, should be encouraged to stop, and offered help to do so, at every opportunity.
  - Smoking cessation efforts both opportunistic and structured support should be integral to the work of all health care professionals and in all healthcare settings.
  - A co-ordinated approach should be taken to the provision of smoking cessation services, through the continuum of health settings, to ensure that all smokers can

access smoking cessation advice/therapy at a time which maximises their opportunity to quit.

- These services should be networked so that when patients move between different settings they experience a smooth transition to a similar programme thereby reducing the risk of relapse.

3 \*For the smokers admitted to hospital, NRT should be made available without cost implication for the hospital.

4 \*All smokers in contact with smoking cessation services should be offered free NRT. This issue of NRT provision through structured smoking cessation programmes needs wider discussion.

**Objective 3: Provide patients and carers with comprehensive, user-friendly information at the time of diagnosis and throughout course of illness.**

**Recommendations**

1. \*Standardised up to date information for patients and carers should be developed nationally and adapted for local and individual use. Such information should be in line with other relevant information on risk factors and common pathway co-morbidities.

**Objective 4: Advocate for respiratory health where people live, work and play.**

**Recommendations**

1. \*Respiratory health as exemplified by COPD should be a policy driver in promoting healthy respiratory environments such as housing, heating standards, air quality including vehicle emissions and environmental tobacco smoke (ETS).
2. \*COPD prevalence and mortality should be acknowledged as a national marker of socio-economic inequalities and addressed in a targeted manner.
3. \*The National Steering Group should:
  - Place COPD and its risk factors on agenda for all relevant organisations
  - Strengthen patient support groups as advocates
  - Empower the patient community to manage their own health needs
  - Support relevant professional organisations to improve awareness, education, and diagnosis for their patients.

|               |   |
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| <b>Goal 3</b> | <b>Ensure timely access to comprehensive and integrated services in appropriate settings</b>  |
| Objectives    | <ol style="list-style-type: none"> <li>1. Implement structured integrated programmes and services to ensure a comprehensive quality approach for all people with COPD.</li> <li>2. Ensure all patients are managed according to evidence based guidelines at all stages of their disease, while also addressing their co-morbid condition.</li> </ol> |

|  |   |
|--|---|
|  | <p>3. Provide care in the most appropriate setting with all necessary supports according to the patients' needs and severity of illness.</p> <p>4. Facilitate a smooth and seamless patient journey within the required health care settings, and when required, input from other services.</p> |
|--|---|

**Objective 1: Implement structured integrated programmes and services to ensure a comprehensive quality approach for all people with COPD.**

**Recommendations**

1. \*The Health system should move away from a reactive model to a more structured, planned approach for patients, which addresses the complexity of people with multiple chronic health conditions, including COPD, as opposed to the single disease approach.
2. \*The National Steering group should ensure that COPD proofing is an integral part of other relevant health strategies.
  - This should include a cohesive comprehensive approach to disease prevention efforts in areas such as social policies, entitlements, screening, health services configuration etc.
  - Services, which include prevention, pre-hospital care, acute hospital care, rehabilitation and post hospital care, should be resourced and available to all patients who could benefit from these services.
3. \*Structured integrated COPD care pathways in both primary and secondary care settings reflecting the quality dimensions of accessibility, acceptability, equity, efficiency, effectiveness and relevance should be in place.
4. \*Primary care should play a central role in managing and co-ordinating care for patients with COPD, many of whom have more than one chronic disease, and attend different care providers.
  - Primary Care should provide early identification and diagnosis of COPD, patient education and self-management, reduction of risk factors, initiation of pharmacological and non-pharmacological treatment, management of acute exacerbations, long term follow-up and supportive end-of-life care.
  - Integrated care pathways should include dynamic individual shared care plans, across settings and disciplines with Primary Care professionals as lead health care workers.
5. \*Care should involve a seamless pathway for patients with COPD between disciplines and settings. This should be delivered through a shared care approach.
  - Those delivering shared care should have clear roles and responsibilities together with explicit criteria and agreed communication procedures with particular emphasis on the transition points between disciplines, services and settings.

- As part of the shared care seamless model approach, the skills and expertise of hospital based respiratory professionals should meet/reach/link out to patients and primary care professionals through models of care (such as outreach programmes, early discharge, hospital in the home, rapid access clinics etc).
6. \*Specialist services should be planned and delivered on a demographic basis based on the health needs of the population, in this case of patients with COPD.
- Each acute hospital should ensure provision of integrated care for people with COPD, which adheres to best practice guidelines across all teams and settings within the hospital and all points of contact with patients.
  - There should be standard protocols for people with COPD in both ED and MAU documenting indications for referral to specialist respiratory services.
  - As recommended in Goal 4 and as per the Guidelines (Chapter 7), evidence based pulmonary rehabilitation programmes should be accessible to all patients with COPD, and should be offered to all patients with COPD starting at time of diagnosis.

**Objective 2: Ensure all patients are managed according to evidence based guidelines at all stages of disease, while also addressing their co-morbid conditions.**

**Recommendations**

1. \*The national clinical guidelines (chapter 7) should be implemented and evaluated on an ongoing basis.
  - The national clinical guidelines (chapter 7) for COPD should be disseminated and implemented in all relevant settings with the addition of relevant region/local specific service information.
2. \*National guidelines on oxygen should be developed to complement national COPD guidelines taking cognisance of concerns about availability, appropriateness of use, and administrative procedures.
3. COPD is often accompanied by de-conditioning, co-morbid illnesses even in patients with mild disease such that health status can be substantially compromised.
  - Management of the person with COPD should both take cognisance of and address co-morbidities.
  - Health Care Professionals managing persons with other illnesses should also take cognisance of and address issues of COPD where relevant.
  - All patients with COPD under the care of a health professional in any health setting, regardless of cause of attendance, should have that care delivered which takes cognisance of COPD national guidelines and local protocols for same.
  - \*Service delivery models, guidelines, protocols, patient pathways should reflect the above points.
4. \*Smoking cessation is the single most effective intervention to reduce the risk of developing COPD. As smoking is an addiction and a chronic relapsing disorder, all smokers should be

offered all treatment supports to overcome this disorder (see Goal 1) and smoking cessation activities should be integrated throughout the healthcare system.

5. \*There should be targeted timely spirometric testing of symptomatic people at risk of developing COPD.

- Spirometry services should be delivered by appropriately trained staff and adhere to relevant quality processes.
- The provision of spirometry services should be developed in line with local needs and structures which could include all or some of the following settings for delivery: Primary care setting, Community delivered, Hospital outreach, Hospital based pulmonary function laboratory etc.
  - As local delivery structures will influence how spirometry will be delivered some of the options considered by this group are included in Appendix 10.

6. \*The palliative care needs of people with COPD need to be considered in all stages of their illness trajectory. To achieve this, health care professionals need basic competencies in palliative care, and develop a collaborative approach with their specialist care professional colleagues to develop local service models. A palliative component should be included in pulmonary rehabilitation programmes.

**Objective 3 Provide care in the most appropriate setting with all necessary supports according to the patients' needs and severity of illness.**

**Recommendations**

1 \*Current and future services should be co-ordinated, so that aspects common to different disease programmes are not duplicated but are of sufficient capacity to address all who need them. For example, aspects of smoking cessation common to both cardiac and COPD patients.

2 \*Health service capacity, both resources and supports, should be sufficient in numbers, training and equipment to meet needs of people with COPD in the most appropriate setting (See Goal 4).

3. \*Patients with acute exacerbations of COPD should be managed in an appropriate setting and with an appropriate programme, for example self-management at home, home with Primary Care and/or Community Intervention Team, Respiratory outreach, Rapid Access Respiratory opinion, Medical Assessment Unit, hospital in the home, early discharge, acute hospital admission etc, in a manner which integrates primary care, specialist hospital outreach and community in-reach.

- Pulmonary outreach, Hospital in the home (Hith), assisted discharge schemes etc should be used as an alternative way of managing patients with an exacerbation of COPD to both prevent hospital admission and shorten length of stay.

4. \*Patients with an acute exacerbation of COPD with respiratory acidosis despite delivery of controlled oxygen therapy and maximal medical treatment should be assessed for non-invasive ventilation (see Guidelines chapter 7).

- All hospitals receiving acute medical admissions should have arrangements in place for speedy access to non-invasive ventilation 24 hours per day, 7 days per week.
- All hospitals receiving acute medical admissions should have arrangements in place for speedy access to invasive ventilation 24 hours per day, 7 days per week.

5 \*Patients with COPD should be prescribed medications using nebulisers on an ongoing basis only after appropriate assessment and education including infection control.(156)

- Other than those needing palliative care, patients with COPD being considered for nebuliser treatment for long-term chronic disease management should be assessed by a specialist respiratory team.
- Systems should be in place to supply and maintain nebulisers, both in terms of performance, and infection control standards.

**Objective 4: Facilitate a smooth and seamless patient journey within the required health care settings, and when required, input from other services**

**Recommendations**

1 \*Care for people with COPD should move from episodic isolated interventions towards integrated and continuous care. Each region should plan, develop and implement its own arrangements based on population, geography, local specialist services, structures etc including those available or planned for other chronic diseases.

- A starting point for this would be a micro audit of current services.

2 \*The Regional Planning Fora and COPD LITs should ensure that systems are in place so that when the services of other sectors, both statutory and non-statutory, are needed, individuals with COPD and their health service providers can access them in a co-ordinated and timely manner.

|               |   |
|---------------|---|
| <b>Goal 4</b> | <b>Empower patients and carers to actively participate in the management of their condition</b>   |
| Objective     | <ol style="list-style-type: none"> <li>1. Enable patients to contribute to their own well-being and support them and their carers in developing and maintaining skills to manage COPD.</li> <li>2. Encourage patients and their carers to retain and develop social networks.</li> <li>3. Provide support for patients to participate in pulmonary rehabilitation.</li> </ol> |

**Objective 1: Enable patients to contribute to their own well-being and support them and their carers in developing and maintaining skills to manage COPD**

**Recommendations**

1. \*Self management/education programmes as part of the continuum of optimal management of COPD, for patients and carers should be developed and standardised nationally, and adapted for local and individual use.
  - These programmes should be a partnership between health professionals, the patient and their carers, with the objectives of increasing patient compliance with prevention and treatment by:
    - Increasing skills, confidence and knowledge of COPD, its treatment and treatment options
    - Promoting patient self-management ability and responsibility for lifestyle choices and avoidance of risk factors.
  - Patients and their carers should have access to COPD education in all relevant settings and as part of all inter-actions with relevant health care professionals.
  - Healthcare providers should assist patients during stable periods of health to think about their care plan. Where relevant these discussions should prepare patients for potential treatment options during exacerbations some of which might be life-threatening.
2. Each patient should have individualised written information which includes
  - How to recognise and respond to any deterioration in their condition
  - Contact numbers for named health professionals.
3. \*An oxygen alert card, based on a national template should be provided for all patients on oxygen therapy outside the hospital setting.
4. \*Each patient should have a patient held card, based on a national template, to facilitate ease of sharing key information with relevant settings and professionals.
5. Each patient should have an agreed multidisciplinary care plan with input from the patient, the sharing and updating of which will depend on local structures.
6. \*Patient information packs in a variety of formats should be developed nationally, and adapted for local use.
  - Their core content should be developed in line with international best practice (chapter 7)
  - A distribution system for these packs, supported by a database with all potential points of contact with patients, carers, health care workers, should be in place to ensure that supply meets need in a systematic manner.
7. In addition to the above information packs, specific groups of patients will have additional needs which should be addressed such as contact details for local patient support groups etc.

## **Objective 2: Encourage patients and their carers to retain and develop social networks**

### **Recommendations**

1. All patients with COPD and their carers should be encouraged to re-establish and retain an active lifestyle in order to promote physical and psychological well-being.

2. \*Communities should be facilitated to encourage community-wide participation in activities, by developing facilities which are accessible to all, including people with COPD.
3. \*Employers and work settings should be supported to facilitate participation of employees with COPD in their employment.
4. \*A national system should drive and support development of a network of COPD patient support groups.
  - o All patients with COPD, irrespective of locality or health status should be able to link with members of a COPD support group, both on an individual and group basis.
  - o All patients with COPD should be encouraged to participate in their local COPD support group

**Objective 3: Provide support for patients to participate in pulmonary rehabilitation.**

**Recommendations**

1. Pulmonary rehabilitation should be a multidisciplinary programme of care, with multi-component interventions, which are individually tailored for patients.
2. \*A national approach is required to develop a network of local evidence based pulmonary rehabilitation programmes, which accepts referrals from primary care and hospitals, and is available to all patients with COPD.
3. \*Supports should be provided so that patients can participate in pulmonary rehabilitation at a stage in their illness when optimal benefit is possible, and in settings, and at times which will maximise their participation.
4. \*Opportunities should be explored to collaborate with other relevant rehabilitation programmes, which share elements with COPD while ensuring provision of the COPD component for disease specific management.

| <b>Goal 5</b> | <b>Enable health care workers to deliver an evidence based service</b>  |
|---------------|---|
| Objective     | <ol style="list-style-type: none"> <li>1. Develop and deliver an evidence based approach to COPD.</li> <li>2. Build capacity among all health care staff who care for people with COPD.</li> <li>3. Ensure health care workers have access to the necessary resources to effectively implement best practice.</li> <li>4. Develop information systems to support delivery and evaluation of evidence based services.</li> </ol> |

**Objective 1: Develop and deliver an evidence based approach to COPD**

**Recommendations:**

1. \*Evidence-based guidelines for COPD presented in Chapter 7 should be implemented.

2. \*The National Steering Group should work via the Regional COPD planning fora to ensure that the guidelines are disseminated, adapted for local use and implemented.
3. \*The Regional COPD planning fora in conjunction with COPD Local Implementation Teams (LITs) should ensure that that the planning, resourcing and implementation of COPD services reflect the evidence-based guidelines contained in this document.

## **Objective 2: Build capacity among all health care staff who care for people with COPD**

### **Recommendations**

1. \*National training programmes should be developed and validated in a number of aspects of respiratory care for delivery to relevant professionals, in a variety of formats and locations.
  - Appropriate training and support should be provided to ensure that all health care staff have the necessary skills to provide optimal care for people with COPD. These should include smoking cessation, spirometry testing and its interpretation, inhaler techniques, nebuliser use, care and maintenance, palliative care recognition and skills etc.
  - Continuous Professional Development (CPD) programmes, tailored to the needs of professionals, their patients and settings, should be developed, resourced and rolled out on an ongoing basis.
2. \*An evidence based approach to the management of people with COPD should be a core competency in all relevant under-graduate and post-graduate curricula.

## **Objective 3 Ensure health care workers have access to the necessary resources to effectively implement best practice**

### **Recommendations**

1. \*The necessary resources to effectively implement best practice should be identified and quantified in a systematic manner, prioritised and delivered in a realistic time frame.
2. \*Sufficient human resources and appropriate skills mix, should be available to effectively implement best practice and should reflect the multi-disciplinary integrated approach required for the care of people with COPD.

## **Objective 4: Develop information systems to support delivery and evaluation of evidence based services.**

### **Recommendations**

- 1 \* Information and Audit should be an integral part of all aspects and activities of health staff, teams and services.
- 2 \*As quality monitoring frameworks are a prerequisite for the delivery of COPD services and for the achievement of optimal clinical outcomes for patients, a system of quality assurance and accreditation should be introduced.

3. \*The National Steering Group should guide policy, service delivery and research and should develop a system which identifies and assesses evidence based initiatives and ensures their dissemination as appropriate.

4 \*National performance indicators for COPD services and outcome targets for people with COPD should be specified, by the National Steering Group.

- HSE service plans should incorporate these indicators and targets.
- The National Steering Group's annual reports should monitor progress on these performance indicators and targets
- The quarterly updates and annual progress reports of each LIT and Regional Planning Fora should reflect these indicators and targets.

5 \*Appropriate information systems should be in place to report data on COPD patients in all settings which they attend along the continuum from Primary Care to Tertiary Care, from risk factor prevalence and prevention to terminal care.

- These systems should be monitored systematically at local, regional and national level.
- Information systems should support the development of integrated care pathways.
- Practice-based registers of people with COPD should be actively encouraged.
- There should be a national system for provision of home oxygen, in line with its status as a prescribed treatment to include prescription, delivery and monitoring, which ensures its cost effective provision.

## **8.4 Conclusions**

To achieve the vision and mission set out above, the HSE requires an approach to respiratory disease including COPD which takes action both on risk factors and self management support, which delivers quality integrated health care services, and which ensures that people with respiratory disease can move between the different levels of complexity of care. They can then return to or remain at the least complex and most appropriate level with its associated cost benefit and reduced morbidity. The approach proposed will achieve this.

The development and implementation of this strategy will ensure early and appropriate diagnosis of patients with respiratory disease including COPD. It will also ensure best practice in the management of patients, support in smoking cessation and in pulmonary rehabilitation together with strengthening community-based services, and reducing both hospitalisations and lengths of acute hospital for patients. This will result in improved quality of life for those affected including reduced mortality from respiratory disease including COPD. A cohesive comprehensive approach contributed to a significant reduction in cardio-vascular mortality and morbidity. The same can be achieved for COPD in particular and Respiratory disease in general.

## Abbreviations and Acronyms

AAT: Alpha One Anti-Trypsin  
ADL: Activities of Daily Living  
A&E: Accident and Emergency Department (ED)  
ANAIL: Respiratory Nurses Association of Ireland  
ATS: American Thoracic Society

BDU: Bed Days Used  
BMI: Body Mass Index  
BODE: BMI, Obstruction, Dyspnoea, Exercise Capacity  
BTS: British Thoracic Society

CAT: Computerised Axial Tomography  
CHD: Coronary Heart Disease  
CI: Confidence Interval  
COPD: Chronic Obstructive Pulmonary Disease  
CPAP: Continuous Positive Airway Pressure  
CPD: Continuous Professional Development  
CSO: Central Statistics Office  
CVD: Cardio-vascular Disease  
CXR: Chest Radiography

DALYs: Disability Adjusted Life Years  
DFLE: Disability Free Life Expectancy  
DM: Diabetes Mellitus  
DOHC: Department of Health and Children  
DPI: Dry Powder Inhaler  
DPS: Drug Payment Scheme

ECG: Electrocardiography  
ED: Emergency Department  
EHMU: European Health Expectancy Monitoring Unit  
ERS: European Respiratory Society  
ESRI: Economic and Social Research Institute  
ETS: Environmental Tobacco Smoke  
EU: European Union

FEV<sub>1</sub>: Forced Expiratory Volume in one second  
FVC: Forced Vital Capacity

GOLD: Global Initiative for Chronic Obstructive Lung Disease

GARD: Global Alliance for Respiratory Disease

GMS: General Medical Services

GP: General Practitioner

HCW: Health Care Worker

HDU: High Dependency Unit

HIPE: Hospital In-patient Enquiry

HITH: Hospital in the Home

HRQoL: Health Related Quality of Life

HSE: Health Service Executive

ICS: Inhaled Corticosteroids

ICT: Information & Communications Technology

ICU: Intensive Care Unit

IPH: Institute of Public Health

ITS: Irish Thoracic Society

ICGP: Irish Society of General Practitioners

kPa: Kilopascal

LE: Life Expectancy

LHO: Local Health Office

LIIS: Living in Ireland Survey

LIT: Local Implementation Team

LOS: Length of Stay

LTOT: Long Term Oxygen Therapy

LTRA: Leukotriene Receptor Antagonists

LVRS: Lung Volume Reduction Surgery

MDI: Metered Dose Inhaler

MRC: Medical Research Council

NACE: European Industrial Activity Classification

NCPE: National Centre for Pharmaco-economics

NHO: National Hospital Office

NICE: National Institute of Clinical Excellence

NIV: Non-Invasive Ventilation

NRT: Nicotine Replacement Therapy

NSAID Non Steroidal Anti Inflammatory Drug

PaCO<sub>2</sub>: Partial pressure of carbon dioxide in arterial blood

PA: Pulmonary Artery

PCCC: Primary, Community & continuing Care

PCRS: Primary Care Reimbursement Service

PCT: Primary Care Team

PEF: Peak Expiratory Flow

PRP: Pulmonary Rehabilitation Programme

QNHS: Quarterly National Household Survey

RCT: Randomised Control Trial

RR: Relative Risk

SCO: Smoking Cessation Officer

SEG: Socio-economic Group

SOB: Shortness of breath

SpO<sub>2</sub>: Oxygen saturation

TB: Tuberculosis

URTI: Upper Respiratory Tract Infection

WHO: World Health Organisation

WTE: Whole Time Equivalent

YPLL: Years of Potential Life Lost

## Glossary

**Allergen:** a substance which can cause an allergy (when the body reacts badly to something) but which is harmless to most people.

**Ambient air:** the air that we breathe and which surrounds us as we go about daily living.

**Ambulatory oxygen:** a portable oxygen supply that can be moved around with the patient.

**Arterial Gas Tension:** the pressure, in mm Hg, of a gas in the arterial blood.

**BODE score:** composite measure of body mass index, airflow obstruction, dyspnoea and exercise capacity.

**Bronchiectasis:** the bronchial tubes become enlarged and distended forming pockets where infection may gather. The walls become damaged which results in impairment to the lung's complex cleaning system. Mucus and bacteria accumulate, infection develops and is difficult to remove.

**Bronchitis:** inflammation of the bronchi (lung airways) that causes cough and sputum (phlegm) production.

**Bronchodilators:** substances that relax contractions of the smooth muscle of the bronchioles to improve ventilation to the lungs.

**Chronic Diseases:** diseases for which there is no cure and which persist for at least six months

**Chronic Obstructive Pulmonary Disease (COPD):** the name given to a condition where people cannot breathe in and out properly because of long-term damage to the lungs. In COPD, the airways have become blocked ('obstructed') to some extent, and the air sacs may have become damaged. Causes of the blockage include an increased amount of mucus in the airways and narrowing of the passages as a result of the airway walls becoming thickened.

**Clinical Networks:** co-ordinated groups of health care professionals and organisations from primary, secondary and tertiary care working together to ensure a high quality clinically effective service.

**Co-morbidities:** the presence of illnesses or conditions that coexist with or are additional to the initial diagnosed illness.

**Continuous Positive Airways Pressure (CPAP):** patients wear a special nose or face mask at night that is connected to an airflow generator. The increased air pressure keeps the airway open and those with sleep apnoea can get the quality sleep they need.

**Cor Pulmonale:** a heart condition that happens as a consequence of a lung condition such as COPD.

**Corticosteroids:** substances that reduce the inflammation of the smooth muscle of the bronchioles to improve ventilation to the lungs. Naturally occurring hormone from the adrenal glands, with multiple effects on metabolism, including reduction of inflammation.

**Domiciliary oxygen:** oxygen prescribed for patients in the home.

**Dyspnoea:** difficult breathing

**Echocardiograph:** diagnostic procedure, using ultrasonic waves, for studying the structure and motion of the heart

**Emphysema:** a chronic obstructive pulmonary disease in which the alveoli and airways are damaged. It is the damage to the lung tissue in COPD that affects the ability of the air sacs to transfer air into the body and that makes the airways floppy.

**Exacerbation** is the worsening or flare-up of a condition

**Hypercapnoea /Hypercapnoeic:** an abnormally high level of carbon dioxide level in arterial blood

**Hypercapnic Respiratory Failure** may happen during an exacerbation. The patient's blood becomes saturated with carbon dioxide and they are unable get enough oxygen into their blood. In these circumstances NIV should be used

**Hypoxaemia:** a deficiency of oxygen in the arterial blood

**Hypoxia:** reduced level of oxygen in the tissues

**Incidence:** the rate at which something happens

**Inhaler:** small devices, which ensure that very small amounts of medication are delivered directly into the lungs. It is important to ensure that an inhaler device delivers the drugs to the airways consistently and in the right quantity.

**Ischaemic Heart Disease:** pathological condition of the myocardium caused by coronary artery disease

**Life expectancy:** Life expectancy is a summary measure of the health status of a population. It is defined as the average number of years an individual of a given age is expected to live if current mortality rates continue to apply.

**Lower Respiratory Tract:** consists of the windpipe (trachea) and the lungs (including the bronchi, bronchioles, and alveoli)

**Myopathy:** disease of the muscles or muscle tissues; characterised by muscle weakness and wasting, as well as pain and tenderness.

**Multi-disciplinary teams:** teams of people from different areas of expertise; a group of health professionals who work together to help plan and carry out treatment for patients, including medical, nursing and allied health professionals.

**Non-invasive ventilation (NIV):** a method of helping a person to breathe artificially. The person wears a mask that covers the nose (or a full face mask that covers the nose and

mouth). This is connected to a small machine that pushes air through the mask and into the person's lungs.

**Nebulisers:** devices that convert liquid medicine into an aerosol (or mist) that can be breathed in. This allows higher doses of medicines to be taken into the lungs.

**Oxidative Stress:** impaired performance of cells caused by the presence of an excess of reactive oxygen/free radicals

**Oximetry:** a relatively inexpensive, non-invasive, simple and reliable means to determine oxygen saturation in arterial blood

**Palliative care:** care that aims to achieve the best quality of life possible for the patient and their family through active identification, holistic assessment and appropriate management of problems, when progressive advanced disease is not responsive to curative treatment

**Peak Expiratory Flow Measurement:** measurement of the ability to blow air out of the lungs

**Pharmacotherapy:** treatment of disease with prescription medications

**Pneumonia:** an acute or chronic disease marked by inflammation of the lungs and caused by viruses, bacteria, or other micro organisms and sometimes by physical and chemical irritants. Symptoms include shortness of breath, fever and a productive cough.

**Pneumothorax:** accumulation of air or gas in the space between the lung and chest wall, resulting in partial or complete collapse of the lung. Symptoms include shortness of breath and chest pain.

**Polycythaemia:** a condition marked by an abnormally large number of red blood cells in the circulatory system; can occur as a primary disease of unknown cause, or in association with respiratory or circulatory disease

**Prevalence:** proportion of a population of people who are experiencing a condition or disease at any given time.

**Primary Care:** the first point of contact for people outside hospitals in local settings. Primary care health professionals include local GPs, community nurses, social workers, pharmacists, physiotherapists, occupational/speech/language therapists, opticians and dentists among others.

**Pulmonary Hypertension:** a condition of abnormally high pressure within the pulmonary circulation

**Pulmonary Oedema:** a build up of fluid in the lungs, which causes breathlessness, particularly when lying flat or exercising

**Pulmonary Rehabilitation Programme:** Programme designed to improve exercise tolerance and quality of life, whilst reducing dyspnoea, anxiety and depression. An aid to self-management. It is a programme of care and activities co-ordinated by different types of health care professionals who work as a team to help you live as normal a life as possible. The programme should be designed specifically for the individual, with their full involvement. It should include exercises, information, diet and other ways of dealing with COPD.

**Right Heart Failure/ Right Ventricle Failure:** a condition in which the heart fails to pump enough blood through the lungs. Right-sided failure means that blood does not get to the lungs to be oxygenated. Instead it pools in the veins causing swelling in the tissues, especially the legs and abdomen.

**Secondary Care:** treatment/care delivered and received mainly in an acute hospital setting.

**Self Management:** a treatment approach in which patients assume responsibility for their behaviour, changing their environment, and planning their future.

**Six minute walk test:** standardised test to measure the distance walked in six minutes, as a measure of exercise capacity.

**Sleep Apnoea:** sleep disorder where breathing is interrupted repeatedly, resulting in inadequate sleep. The airway becomes blocked and breathing stops repeatedly during sleep. Impulses from the brain then arouse the person enough to restart breathing but not enough that the person is fully awake. This cycle repeats hundreds of times during sleep and results in sleep deprivation. Symptoms include snoring, daytime sleepiness and waking un-refreshed in the mornings.

**Socio Class and Social-Economic Groupings (SEGs):** ways of classifying the population based on occupation.

**Spirometry:** a breathing test used to diagnose COPD and to monitor any changes in lung function over time

**Tachypnoea:** abnormally fast breathing rate

**Telemedicine:** the delivery of healthcare services, where distance is a critical factor, by healthcare professionals using information and communications technologies for the exchange of information for diagnosis, treatment and for the continuing education of healthcare providers.

**Tertiary Care:** treatment or care delivered in a specialist centre such as a regional centre attached to a major hospital. An example is the lung transplant centre attached to the Mater Hospital.

**Type 2 Respiratory Failure:** ventilatory failure characterised by the inability to adequately exhale the carbon dioxide generated by the body, e.g. due to a decrease in the area of lung available for gas exchange as occurs in COPD

**Upper Respiratory Tract:** includes the mouth, pharynx, tonsils, sinuses and middle ears and is lined by a moist mucosa.

**Vaccine:** a substance which contains a harmless form of a virus or bacterium and which is given to a person or animal to prevent them from getting the disease which the virus or bacterium causes.

## Appendix 1 Members: National COPD Group

|                             |   |
|-----------------------------|---|
| Ciara Cassidy               | Irish Society of Chartered Physiotherapists   |
| John Cuddihy                | Chronic Diseases, Specialist Public Health Medicine, Strategic Planning, Population Health, HSE                           |
| John Devlin                 | Deputy Chief Medical Officer, Department of Health & Children   |
| William Ebbitt              | Health Promotion, Population Health, HSE  |
| Angela Fitzgerald           | National Hospitals Office, HSE  |
| JJ Gilmartin                | Respiratory Consultant: President Irish Thoracic Society  |
| Ann Kennelly                | Primary Community & Continuing Care, HSE  |
| Triona McCarthy             | Winter Initiative, Community Interventions, Specialist Public Health Medicine, Strategic Planning, Population Health, HSE |
| Tim McDonnell               | Respiratory Consultant: Irish Thoracic Society  |
| Máire O'Connor              | Chair, Specialist Public Health Medicine, Strategic Planning, Population Health, HSE                                      |
| Miriam Owens:               | Medical Secretary, Specialist Registrar Public Health Medicine, Strategic Planning, Population Health, HSE                |
| Jennifer Quinn              | Respiratory Nurse Specialist: ANAIL   |
| Maeve Raeside               | Project Co-Coordinator (Administration), Strategic Planning, Population Health, HSE                                       |
| Mark Walsh<br>Practitioners | General Practitioner: Chair, Irish College of General   |

## Appendix 2 Alpha-1 anti-trypsin (AAT) deficiency

| Alpha 1 variants | Phenotype | What does It Mean?   |
|------------------|-----------|--|
| Normal           | MM        | Does not have the disorder, does not carry any altered AAT genes   |
| Carrier          | MZ/MS     | Mild to moderate AAT deficiency – may develop disease symptoms, carries an altered AAT gene  |
| AAT Deficiency   | ZZ/SZ/SS  | Moderate to severe AAT deficiency – will develop disease eventually, carries two altered AAT genes. <ul style="list-style-type: none"> <li>• ZZ develop disease in 20s if smoke, in 40s/50s if don't smoke</li> <li>• SZ develop disease but less at risk if don't smoke</li> <li>• SS develop disease if smoke</li> </ul> |

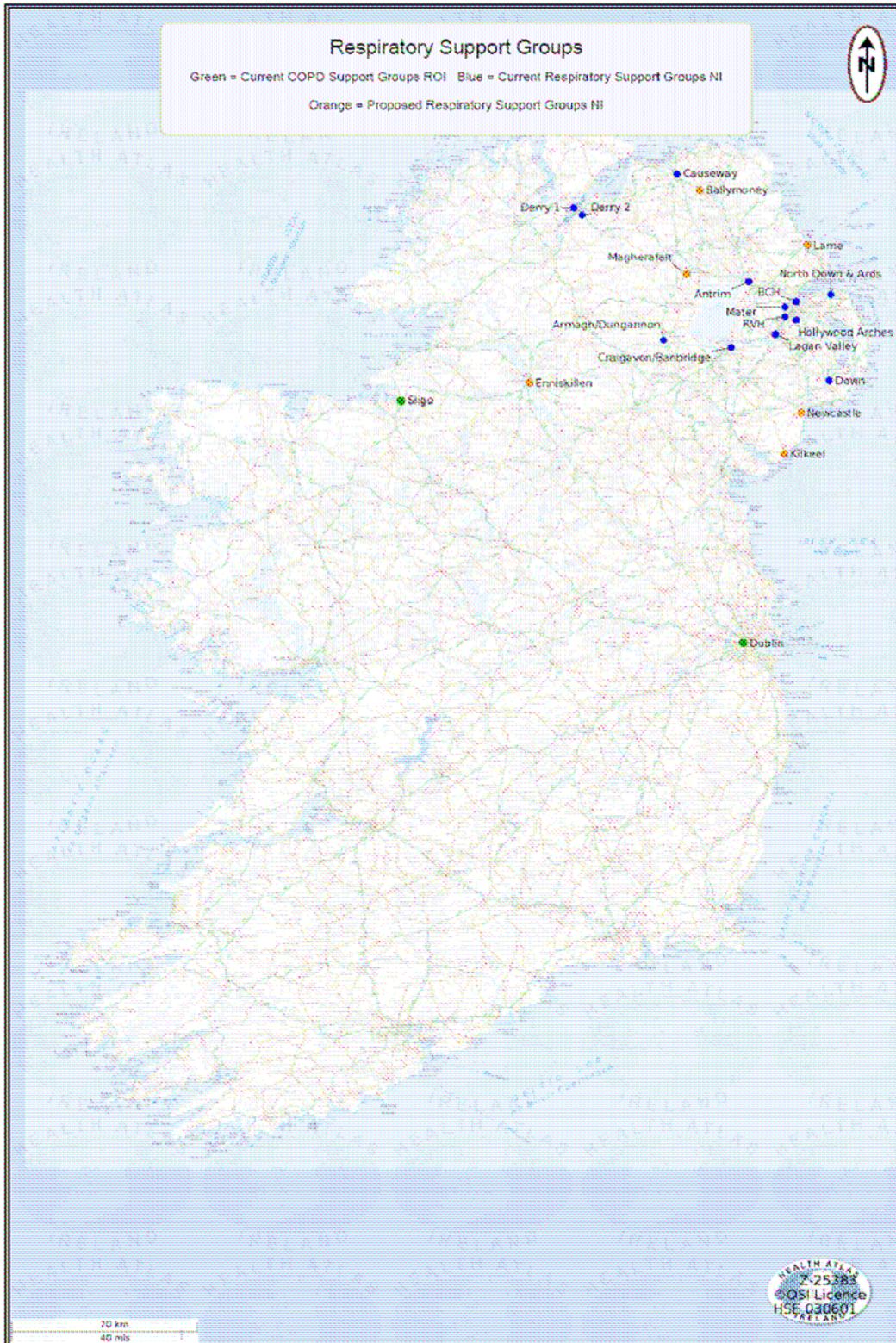
### Results of Testing (76)

|                            |     |
|----------------------------|-----|
| Stage 1 (Mild COPD)        | 37% |
| Stage 2 (Moderate COPD)    | 19% |
| Stage 3 (Severe COPD)      | 44% |
| Stage 4 (Very severe COPD) | 0%  |

### Alpha (AAT) deficiency Screening Centres

| County    | Hospital  |
|-----------|---|
| Dublin    | Beaumont Hospital<br>Mater Misericordiae Hospital<br>Tallaght Hospital<br>Peamount Hospital<br>St James's Hospital<br>Connolly Hospital |
| Westmeath | Midland Regional Hospital,  |
| Louth     | Our Lady of Lourdes Hospital,   |
| Galway    | University College Hospital,  |
| Cork      | Cork University Hospital<br>Mercy University Hospital   |
| Limerick  | Midwestern Regional Hospital  |
| Donegal   | Letterkenny General Hospital  |
| Cavan     | Cavan General Hospital  |

### Appendix 3 COPD support groups: ROI, NI



### Appendix 4 Inpatient Activity for COPD Hospitalisations (Principal Diagnosis) Aged 35+ 2006

| Hospital                      | Inpatient Discharges | Bed Days Used | Mean LOS    |
|-------------------------------|----------------------|---------------|-------------|
| Lourdes Drogheda              | 170                  | 1769          | 10.4        |
| Cavan                         | 285                  | 2722          | 9.6         |
| Dundalk                       | 263                  | 2533          | 9.6         |
| Monaghan                      | 138                  | 1079          | 7.8         |
| Navan                         | 212                  | 1615          | 7.6         |
| <b>Total North-East</b>       | <b>1068</b>          | <b>9718</b>   | <b>9.1</b>  |
| Mater                         | 433                  | 6787          | 15.7        |
| Connolly                      | 202                  | 1361          | 6.7         |
| Beaumont                      | 470                  | 5388          | 11.5        |
| <b>Total Dublin North</b>     | <b>1105</b>          | <b>13536</b>  | <b>12.2</b> |
| Loughlinstown                 | 203                  | 2434          | 12          |
| St Vincent's                  | 394                  | 6316          | 16          |
| St Luke's                     | 2                    | 25            | 12.5        |
| St James's                    | 502                  | 6383          | 12.7        |
| St Michael's                  | 150                  | 1951          | 12.8        |
| <b>Total Dublin South</b>     | <b>1251</b>          | <b>17109</b>  | <b>13.7</b> |
| Naas                          | 354                  | 5734          | 16.2        |
| Peamount                      | 202                  | 2675          | 13.2        |
| AMNCH (Tallaght)              | 292                  | 4375          | 15          |
| Tullamore                     | 304                  | 3617          | 11.9        |
| Mullingar                     | 281                  | 2155          | 7.7         |
| Portlaois                     | 165                  | 1186          | 7.2         |
| <b>Total Dublin Midlands</b>  | <b>1598</b>          | <b>19742</b>  | <b>12.4</b> |
| Waterford Regional            | 439                  | 4281          | 9.8         |
| St. Luke's Kilkenny           | 407                  | 4157          | 10.2        |
| Wexford                       | 388                  | 2809          | 7.2         |
| Clonmel                       | 345                  | 2846          | 8.2         |
| <b>Total South-East</b>       | <b>1579</b>          | <b>14093</b>  | <b>8.9</b>  |
| Mercy Cork                    | 302                  | 3364          | 11.1        |
| South Infirmary Victoria Cork | 188                  | 1901          | 10.1        |
| Mallow                        | 147                  | 756           | 5.1         |
| Cork University               | 240                  | 2770          | 11.5        |
| Tralee                        | 242                  | 2580          | 10.7        |
| <b>Total South</b>            | <b>1119</b>          | <b>11371</b>  | <b>10.2</b> |
| Limerick Regional             | 404                  | 3798          | 9.4         |
| St John's Limerick            | 196                  | 2042          | 10.4        |
| Ennis                         | 271                  | 1900          | 7           |
| Nenagh                        | 180                  | 1362          | 7.6         |
| <b>Total Mid-West</b>         | <b>1051</b>          | <b>9102</b>   | <b>8.7</b>  |
| Roscommon                     | 216                  | 2021          | 9.4         |
| Portiuncula                   | 266                  | 2173          | 8.2         |
| University Hospital Galway    | 174                  | 2119          | 12.2        |
| Mayo General                  | 345                  | 2421          | 7           |
| Merlin Park                   | 262                  | 2415          | 9.2         |

|                              |              |               |             |
|------------------------------|--------------|---------------|-------------|
| Letterkenny                  | 382          | 2618          | 6.9         |
| Sliog                        | 296          | 2779          | 9.4         |
| <b>Total West North-West</b> | <b>1941</b>  | <b>16546</b>  | <b>8.5</b>  |
| <b>Grand Total</b>           | <b>10712</b> | <b>111217</b> | <b>10.4</b> |

DRAFT

## Appendix 5 Service Deficits

### Service gaps as perceived from Physiotherapy survey

- 5 acute hospitals have no provision for outpatient physiotherapy services.
- There are no dedicated physiotherapists providing a service for COPD inpatients in any of the acute hospitals. These patients form part of the respiratory service or general service caseload.
- Only 2 acute hospitals have an outreach programme.
- PRP only available in 8 acute hospitals and 1 Primary Continuing and Community Care (PCCC) site.

### Acute hospitals deficits: From Physiotherapy survey

- No medical assessment unit
- Lack of appropriate treatment space on ward / gym areas
- No NIV service. No follow up post discharge for COPD patients discharged on home NIV
- No PRP in existence or PRP in existence without dedicated staffing / space /equipment
- Lack of MDT involvement in PRP
- Lack of follow up post-pulmonary rehabilitation
- Lack of outpatient service to all respiratory patients,
- Lack of appropriate treatment space in OPD
- No Outreach service. Where an outreach service exists, no cover weekend and out of hour coverage
- Absence of dedicated time and resources for the physiotherapy staff to manage respiratory caseload across hospital. COPD & other respiratory conditions fall into the general caseload bracket
- Lack of structured screening /follow up
- Patient support service would be very helpful for the patient and for patient interaction.

### PCCC deficits

- Need regular updates on respiratory research and developments
- Limited knowledge in COPD/respiratory treatments. Out of touch with current recommendations
- No specialised respiratory physiotherapy staff - Need clinical specialist in PCCC
- As we see few patients with COPD, danger of deskilling
- Limited staff - Staffing levels do not permit for a quick response to more than one pt at a time

- Lack of resources means no co-ordinated or structured services, work v much on ad hoc basis
- Don't have resources to start any new programmes for clients. If the primary care strategy was rolled out as originally envisaged these clients would benefit from the extra health promotion and prevention. It remains to be seen what can actually happen
- A dedicated OPD service for pts with COPD
- No PRP. Need community based PRP
- No preventative or health promotion service
- Lack of GP awareness of role of physiotherapy in respiratory conditions
- No integrated care approach between GP/physiotherapy/PHN in community. Possibly primary care reform will change this. No interaction between acute and community
- Deficit in referral or identification of COPD patients to palliative care services.

**Service gaps as perceived from Respiratory Nurse Specialist Survey (ANAIL):**

**Main Deficits Cited (ANAIL)**

- Lack of Outreach/Early Discharge Programmes
- Palliative Support at home
- NIV long term support
- Lack of Respiratory Consultants
- Lack of Transport in rural areas
- Limited diagnostic services
- LTOT and NIV Clinics
- Lack of Respiratory Assessment Units
- Pulmonary Rehabilitation
- Lack of funding and resources.

## Appendix 6

### **(a) Organisations which responded to the stakeholder consultation**

Air Products Ireland  
Allianz Corporate  
Alpha One Foundation  
Association of Occupational Therapists of Ireland  
Cystic Fibrosis Registry of Ireland  
Department of Health and Children  
Health and Safety Authority  
Health Services Executive  
Hospital Pharmacists Association of Ireland  
Irish Association of Emergency Medicine  
Irish Association of Respiratory Scientists  
Irish Health Promoting Hospitals  
Irish Hospice Foundation  
Irish Nursing Homes Organisation  
Irish Nutrition & Dietetic Institute  
Irish Practice Nurses Association  
Irish Thoracic Society  
Irish Transplantation Society  
Nursing & Midwifery Planning and Development Unit  
Sligo COPD support group  
Trinity College Dublin  
University College Dublin  
University of Limerick  
VHI  
VIVAS

### **(b) List of Service Providers and Professionals who participated in the consultation by completing the questionnaire and providing comments**

Academics  
Assistant Directors of Nursing  
Assistant National Director Primary Care  
Assistant National Director: NHO: Quality, Risk, Consumers  
Clinical Nurse Managers  
Clinical Nurse Specialists Respiratory  
Coordinators of Services for Older Persons  
Consultants in General Internal Medicine

Consultants Respiratory Physicians  
Dieticians  
Directors of services for elderly  
Directors of Nursing  
Directors of Public Health  
Directors of Public Health Nursing  
Discharge Coordinators  
Environmental Health Officers  
Emergency Medicine Physicians  
Expert Advisory Groups  
General Practitioners  
Health Promotion officers  
Hospital Managers  
Immediate Care Team Managers  
Local Health Managers  
Network Managers  
Nutritionists  
Occupational Health Managers  
Occupational Health Physicians  
Occupational Therapists  
Outreach Coordinators  
Pharmacists  
Physiotherapists  
Primary Care Managers  
Psychologists  
Public Health Nurses  
Respiratory Scientists  
Medical Social Workers  
Smoking Cessation Officers  
Specialist in Public Health Medicine  
Speech & Language Therapists

## Appendix 7: Guidelines

### Appendix 7.1 Term “COPD”

The terms “emphysema” and “chronic bronchitis,” were widely used in the past when describing what is now called COPD. Emphysema, or destruction of the gas exchanging surfaces of the lung (alveoli), is a pathological term that is often incorrectly used clinically and describes only one of several structural abnormalities present in patients with COPD. Chronic bronchitis, or the presence of cough and sputum production for at least 3 months in each of two consecutive years, remains a clinically and epidemiologically useful term. However, it does not reflect the major impact of airflow limitation on morbidity and mortality in COPD patients. Cough and sputum production may precede the development of airflow limitation; conversely, some patients develop significant airflow limitation without chronic cough and sputum production.

### Appendix 7.2 Summary points from international guidelines

|   |
|---|
| <b>Canadian Thoracic Society 2003 (157)</b>   |
| <p>COPD is preventable and treatable</p> <p>Targeted spirometry</p> <p>Smoking cessation</p> <p>Education, especially self-management plans</p> <p>Escalate therapy on individual basis</p> <p>Long-acting anticholinergics and beta<sub>2</sub>-agonist inhalers for patients symptomatic despite short-acting therapy</p> <p>Inhaled steroids should not be used as first line therapy</p> <p>Treat exacerbations promptly with bronchodilators &amp; short course of oral steroids</p> <p>Antibiotics for purulent exacerbations</p> |
| <b>NICE / British Thoracic Society (NICE / BTS) (137)</b>   |
| <p>Diagnose COPD</p> <p>Stop smoking</p> <p>Effective inhaled therapy</p> <p>Pulmonary rehabilitation for all who need it</p> <p>Use of non-invasive ventilation</p> <p>Manage exacerbations</p> <p>Multidisciplinary working</p>   |
| <b>American Thoracic Society /European Respiratory Society (69)</b>   |
| <p>Raise awareness of COPD</p> <p>Inform on the latest advances in the overall pathogenesis, diagnosis, monitoring and management of COPD</p>   |

|   |
|---|
| <p>Promote the concept that COPD is a treatable disease</p> <p>A component for the patient that intends to provide practical information on all aspects of COPD and promote a healthy lifestyle to all patients afflicted with the disease</p>  |
| <p><b>Global Initiative for Chronic Obstructive Lung Disease GOLD (15)</b></p> <ul style="list-style-type: none"> <li>• Relieve symptoms</li> <li>• Prevent disease progression</li> <li>• Improve exercise tolerance</li> <li>• Improve health status</li> <li>• Prevent and treat complications</li> <li>• Prevent and treat exacerbations</li> <li>• Reduce mortality</li> </ul> |
| <p><b>COPD-X Australian and New Zealand (158)</b></p> <p><b>C:</b> Confirm diagnosis and assess severity</p> <p><b>O:</b> Optimise function</p> <p><b>P:</b> Prevent deterioration</p> <p><b>D:</b> Develop support network and self-management plan</p> <p><b>X:</b> Manage eXacerbations</p>  |

**Appendix 7.3 Physical Signs which may be present in patients with COPD**

A number of physical signs may be present in those with COPD, but their absence does not exclude the diagnosis.(15)

- hyperinflated chest
- wheeze or quiet breath sounds
- purse lip breathing
- use of accessory muscles
- paradoxical movement of lower ribs
- reduced crico-sternal distance
- reduced cardiac dullness on percussion
- peripheral oedema
- cyanosis
- raised JVP
- cachexia

**Appendix 7.4 Spirometry**

Spirometry is as important for the diagnosis of COPD as blood pressure measurements are for the diagnosis of hypertension and should be available to all health care professionals.(159)

What is Spirometry?

- Spirometry is a simple test to measure the amount of air a person can breathe out, and the amount of time taken to do so.
- A spirometer is a device used to measure how effectively, and how quickly, the lungs can be emptied.
- A spirogram is a volume-time curve.

Spirometry measurements used for diagnosis of COPD include:

- FVC (Forced Vital Capacity): maximum volume of air that can be exhaled during a forced manoeuvre
- FEV<sub>1</sub> (Forced Expired Volume in one second): volume expired in the first second of maximal expiration after a maximal inspiration. This is a measure of how quickly the lungs can be emptied
- FEV<sub>1</sub>/FVC: FEV<sub>1</sub> expressed as a percentage of the FVC, gives a clinically useful index of airflow limitation
- The ratio FEV<sub>1</sub>/FVC is between 70% and 80% in normal adults; a value less than 70% indicates airflow limitation and the possibility of COPD.

FEV<sub>1</sub> is influenced by the age, sex, height and ethnicity, and is best considered as a percentage of the predicted normal value. There is a vast literature on normal values; those appropriate for local populations should be used.

Most spirometers provide predicted ("normal") values obtained from healthy population studies, and derived from formulae based on height, age, sex and ethnicity. Airflow limitation is considered to be non-reversible when, after administration of bronchodilator medication, the ratio of FEV<sub>1</sub> to forced vital capacity FVC is < 70% and the FEV<sub>1</sub> is < 80% of the predicted value. The ratio of FEV<sub>1</sub> to vital capacity (VC) is a sensitive indicator for mild COPD.(22)

Indications for spirometry are shown in the table below.(160)

**Table Indications for Spirometry(160)**

**Diagnostic**

- To evaluate symptoms, signs or abnormal laboratory tests
- To measure the effect of disease on pulmonary function
- To screen individuals at risk of having pulmonary disease
- To assess pre-operative risk
- To assess prognosis
- To assess health status before beginning strenuous physical activity programmes

**Monitoring**

- To assess therapeutic intervention
- To describe the course of diseases that affect lung function
- To monitor people exposed to injurious agents
- To monitor for adverse reactions to drugs with known pulmonary toxicity

**Disability/impairment evaluations**

- To assess patients as part of a rehabilitation programme
- To assess risks as part of an insurance evaluation
- To assess individuals for legal reasons

**Public health**

- Epidemiological surveys
- Derivation of reference equations
- Clinical research

**Appendix 7.5 Differential diagnosis of COPD vs Asthma(15)**

| Diagnosis | Suggestive Features   |
|-----------|---|
| COPD      | <ul style="list-style-type: none"> <li>Usually onset in mid-life.</li> <li>Symptoms slowly progressive.</li> <li>Often history of tobacco smoking.</li> <li>Dyspnoea during exercise.</li> <li>Largely irreversible airflow limitation.</li> </ul>  |
| Asthma    | <ul style="list-style-type: none"> <li>Onset early in life (often childhood).</li> <li>Symptoms vary from day to day.</li> <li>Symptoms at night/early morning.</li> <li>Allergy, rhinitis, and/or eczema may also present.</li> <li>Family history of asthma.</li> <li>Largely reversible airflow limitation.</li> </ul> |

**Appendix 7.6 Referral for specialist advice(137)**

- A specialist opinion may be helpful at any stage of the disease.
- Referral may be appropriate at all stages of the disease and not solely in the most severely disabled patients (see Table below from BTS /NICE Guidelines).
- Referral may be to establish the diagnosis, to exclude other pathology, to reassure the patient, to reinforce the need to stop smoking, to optimise treatment, or to assess the need for the more complex and expensive therapies appropriate to severe COPD.
- Referrals for specialist advice should be made when clinically indicated.

- Patients who are referred do not always have to be seen by a respiratory physician. In some cases they may be seen by members of the COPD team who have appropriate training and expertise.

**Table Referral for Specialist Advice(137)**

| Reason   | Purpose   |
|--|---|
| There is diagnostic uncertainty  | Confirm diagnosis and optimise therapy                                    |
| Suspected severe COPD  | Confirm diagnosis and optimise therapy                                    |
| The patient requests a second opinion                                  | Confirm diagnosis and optimise therapy                                    |
| Onset of cor pulmonale   | Confirm diagnosis and optimise therapy                                    |
| Assessment for oxygen therapy  | Optimise therapy and measure blood gases                                  |
| Assessment for long- term nebuliser therapy                            | Optimise therapy and exclude inappropriate prescriptions                  |
| Assessment for oral corticosteroid therapy                             | Justify need for long-term treatment or supervise withdrawal              |
| *Assessment for pulmonary rehabilitation                               | *Identify candidates for pulmonary rehabilitation                         |
| Bullous lung disease   | Identify candidates for surgery   |
| A rapid decline in FEV1  | Encourage early intervention  |
| Assessment for lung volume reduction                                   | Identify candidates for surgery   |
| Assessment for lung transplantation                                    | Identify candidates for surgery   |
| Dysfunctional breathing  | Confirm diagnosis, optimise pharmacotherapy and access other therapists   |
| Aged under 40 years or a family history alpha1-antitrypsin deficiency, | Identify alpha1-antitrypsin deficiency consider therapy and screen family |
| Uncertain diagnosis  | Confirm diagnosis   |
| Symptoms disproportionate to lung function deficit                     | Look for other explanations   |
| Frequent infections  | Exclude bronchiectasis  |
| Haemoptysis  | Exclude carcinoma of the bronchus   |

\* Ideally all patients should be referred to rehabilitation at time of diagnosis and as required thereafter.

### **Appendix 7.7 Reduce Risk Factors**

#### Pharmacotherapy for Smoking Cessation

- The BTS/NICE Guidelines recommend that unless contraindicated, bupropion or nicotine replacement therapy combined with an appropriate support programme should be used to optimise smoking quit rates for people with COPD.(137)

- GOLD: Pharmacotherapy (nicotine replacement, bupropion/nortryptiline, and/or varenicline) is recommended when counselling is not sufficient to help patients stop smoking.(15)
- Pharmacotherapy is referred to in the Five As: Assist

#### Occupational Exposures

- Many occupations have been shown to be associated with increased risk of developing COPD, particularly those that involve exposure to fumes and mineral and biological dusts.
- Many occupationally induced respiratory disorders can be reduced or controlled through a variety of strategies aimed at reducing the burden of inhaled particles and gases.(161-163)
  - Implement, monitor and enforce strict, legally mandated control of airborne exposure in the workplace.
  - Initiate intensive and continuing education of exposed workers, industrial managers, health care workers, primary care physicians, and legislators.
  - Educate employers, workers, and policymakers on how cigarette smoking aggravates occupational lung diseases and why efforts to reduce smoking where a hazard exists are important.

#### Indoor and Outdoor Air Pollution(15)

- Although outdoor and indoor air pollution are generally considered separately, the concept of total personal exposure may be more relevant for COPD. While, details on setting and maintaining air quality goals were beyond the scope of the GOLD document, the authors advised that health care providers should consider COPD risk factors including smoking history, family history, exposure to indoor/outdoor pollution) and socio-economic status for each individual patient. The following steps should be considered in individuals at risk of COPD and those diagnosed with COPD.

#### Individuals at risk for COPD:

- Patients should be counselled concerning the nature and degree of their risk for COPD. If various solid fuels are used for cooking and heating, adequate ventilation should be encouraged.
- Respiratory protective equipment has been developed for use in the workplace in order to minimize exposure to toxic gases and particles. Under most circumstances, vigorous attempts should be made to reduce exposure through reducing workplace emissions and improving ventilation measures, rather than simply by using respiratory protection to reduce the risks of ambient air pollution.
- Ventilation and interventions to meet safe air quality standards in the workplace offer the greatest opportunity to reduce worker exposure to known atmospheric pollutants

and reduce the risk of developing COPD, although to date there are no studies to quantify these benefits.

Patients who have been diagnosed with COPD:

- Persons with advanced COPD should monitor public announcements of air quality and be aware that staying indoors when air quality is poor may help reduce their symptoms.
- The use of medication should follow the usual clinical indications; therapeutic regimens should not be adjusted because of the occurrence of a pollution episode without evidence of worsening of symptoms or lung function.
- Those who are at high risk should avoid vigorous exercise outdoors during pollution episodes.
- Air cleaners have not been shown to have health benefits, whether directed at pollutants generated by indoor sources or at those brought in with outdoor air.

### Appendix 7.8 Pharmacotherapy

The medications commonly used in treating people with COPD are shown in the Table below.(15) They are presented in the order in which they would normally be introduced in patient care, based on the level of disease severity and clinical symptoms. Additional details on the drug groups are given in the text which follows the table.

**Table Commonly used formulations of drugs used in COPD**

| <b>Commonly used formulations of drugs used in COPD</b> |                |                               |             |                            |
|---|----------------|-------------------------------|-------------|----------------------------|
| <b>Drug</b>   | <b>Inhaler</b> | <b>Solution for nebuliser</b> | <b>Oral</b> | <b>Vials for injection</b> |
| <b>Beta <sub>2</sub>-agonists: Short-acting</b>         |                |                               |             |                            |
| Salbutamol  | MDI&DPI        | Yes                           |             |                            |
| Terbutaline   | DPI            | -----                         |             |                            |
| <b>Beta 2 –agonists: Long-acting</b>                    |                |                               |             |                            |
| Formoterol  | MDI&DPI        |                               |             |                            |
| Salmeterol  | MDI&DPI        |                               |             |                            |
| <b>Anticholinergics: Short-acting</b>                   |                |                               |             |                            |
| Ipratropium bromide                                     | MDI *          | Yes                           |             |                            |
| Oxipropium bromide                                      | MDI            | Yes                           |             |                            |
| <b>Anticholinergics: Long-acting</b>                    |                |                               |             |                            |
| Tiotropium  | DPI**          |                               |             |                            |
| <b>Methylxanthines</b>                                  |                |                               |             |                            |
| Aminophylline   |                |                               | Yes         | Yes                        |

Theophylline (SR) Yes

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**Inhaled glucocorticosteroids**

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|                |           |       |
|----------------|-----------|-------|
| Beclomethasone | MDI & DPI | Yes   |
| Budesonide     | DPI ***   | Yes   |
| Fluticasone    | MDI & DPI | ----- |
| Triamcinolone  | MDI       | Yes   |

---

**Combination long-acting Beta<sub>2</sub> –agonists plus glucocorticosteroids in one inhaler**

---

|                         |         |
|-------------------------|---------|
| Formoterol/Budesonide   | DPI     |
| Salmeterol /Fluticasone | MDI&DPI |

---

**Systemic glucocorticosteroids**

---

|                     |     |
|---------------------|-----|
| Prednisolone        | Yes |
| Methyl-prednisolone | Yes |

\* MDI metered-dose inhaler                      \*\* DPI Dry powder inhalers

**a) Combination bronchodilator therapy**

Although monotherapy with long-acting beta<sub>2</sub>-agonists appears to be safe, combining bronchodilators with different mechanisms and durations of action may increase the degree of bronchodilation for equivalent or lesser side effects. For example, a combination of a short-acting beta<sub>2</sub>-agonist and an anticholinergic produces greater and more sustained improvements in FEV<sub>1</sub> than either drug alone and does not produce evidence of tachyphylaxis over 90 days of treatment.(164-166)

**b) Glucocorticosteroids**

The effects of oral and inhaled glucocorticosteroids in COPD are much less dramatic than in asthma, and their role in the management of stable COPD is limited to specific indications. The use of glucocorticosteroids for the treatment of acute exacerbations is described in the management of exacerbations of COPD below. Regular treatment with inhaled glucocorticosteroids does not modify the long term decline of FEV<sub>1</sub> in patients with COPD.

Regular treatment with inhaled glucocorticosteroids has been shown to reduce the frequency of exacerbations and thus improve health status for symptomatic COPD patients with Stage III: Severe COPD and Stage IV: Very Severe COPD and repeated exacerbations.

**c) Combination inhaled glucocorticosteroid/bronchodilator therapy:**

An inhaled glucocorticosteroid combined with a long-acting beta<sub>2</sub>-agonist is more effective than the individual components in reducing exacerbations and improving lung function and health status.

**d) Oral glucocorticosteroids: short-term**

Many existing COPD guidelines recommend the use of a short course (two weeks) of oral glucocorticosteroids to identify COPD patients who might benefit from long-term treatment with oral or inhaled glucocorticosteroids. This recommendation is based on evidence that short-term effects predict long-term effects of oral glucocorticosteroids on FEV<sub>1</sub>, and evidence that asthma patients with airflow limitation might not respond acutely to an inhaled bronchodilator but do show significant bronchodilation after a short course of oral glucocorticosteroids.(167)

There is mounting evidence, however, that a short course of oral glucocorticosteroids is a poor predictor of the long-term response to inhaled glucocorticosteroids in COPD.(168, 169) For this reason, there appears to be insufficient evidence to recommend a therapeutic trial with oral glucocorticosteroids in patients with Stage II: Moderate COPD, Stage III: Severe COPD, or Stage IV: Very Severe COPD and poor response to an inhaled bronchodilator.

#### **e) Oral glucocorticosteroids: long-term**

In view of the well-known toxicity of long-term treatment with oral glucocorticosteroids, prospective studies on the long-term effects of these drugs in COPD are limited.

A side effect of long-term treatment with systemic glucocorticosteroids is steroid myopathy, which contributes to muscle weakness, decreased functionality, and respiratory failure in subjects with advanced COPD.(170-172)

Therefore, based on the lack of evidence of benefit, and the large body of evidence on side effects, long-term treatment with oral glucocorticosteroids is not recommended in COPD.

#### **f) Bronchodilators**

Bronchodilators are central to the symptomatic management of COPD.(173-176) The side effects of bronchodilator therapy are pharmacologically predictable and dose dependent. Adverse effects are less likely, and resolve more rapidly after treatment withdrawal, with inhaled than with oral treatment. However, COPD patients tend to be older than asthma patients and more likely to have co-morbidities, so their risk of developing side effects is greater. When treatment is given by the inhaled route, attention to effective drug delivery and training in inhaler technique is essential.

Stimulation of beta<sub>2</sub>-adrenergic receptors can produce resting sinus tachycardia and has the potential to precipitate cardiac rhythm disturbances in very susceptible patients, although this appears to be a rare event with inhaled therapy.

Inhaled Beta<sub>2</sub>-agonists have a relatively rapid onset of action in people with COPD although this is probably slower than in asthma:

- Long-acting inhaled Beta<sub>2</sub>-agonists, such as salmeterol and formoterol, show a duration of effect of 12 hours or more
- The bronchodilating effect of anticholinergics lasts longer than that of short-acting Beta<sub>2</sub>-agonists, with some bronchodilator effect generally apparent up to eight hours after administration
- Tiotropium has a duration of action of more than 24 hours
- Theophylline toxicity is dose related which is a particular problem with the xanthine derivatives because their therapeutic ratio is small and most of the benefit occurs only when near-toxic doses are given
- An inhaled glucocorticosteroid combined with a long-acting beta 2 agonist is more effective than the individual components in reducing exacerbations and improving lung function.

#### **g) Anticholinergics**

Although occasional prostatic symptoms have been reported, there are no data to prove a true causal relationship. A bitter, metallic taste is reported by some patients using ipratropium. Use of wet nebuliser solutions with a face mask has been reported to precipitate acute glaucoma, probably by a direct effect of the solution on the eye.

#### **h) Drug delivery systems**

The devices used to deliver drugs to the lungs are in many respects as important as the drugs themselves. Patient administered metered dose inhalers (PMDI) or dry powder inhalers (DPI) are available to deliver a wide range of medications for the treatment of COPD. Most medications are available in the pressurised meter.

The metered-dose inhaler (MDI) is an aerosol and currently one of the most common types of inhaler. The medication comes out of the inhaler as a mist or spray. An attachment is available for some inhalers, for use by people who have difficulty activating the inhaler.

Metered-dose inhaler (MDI) products contain therapeutically active ingredients dissolved or suspended in a propellant, a mixture of propellants, or a mixture of solvents, propellants, and/or other excipients in compact pressurized aerosol dispensers. An MDI product may discharge up to several hundred metered doses of one or more drug substances. Depending on the product, each actuation may contain from a few micrograms (mcg) up to milligrams (mg) of the active ingredients delivered in a volume typically between 25 and 100 microlitres.

Current designs include pre-metered and device-metered DPIs, both of which can be driven by patient inspiration alone or with power-assistance of some type. Pre-metered DPIs contain previously measured doses or dose fractions in some type of units (e.g., single or multiple presentations in blisters, capsules, or other cavities) that are subsequently inserted into the

device during manufacture or by the patient before use. Thereafter, the dose may be inhaled directly from the pre-metered unit or it may be transferred to a chamber before being inhaled by the patient. Device-metered DPIs have an internal reservoir containing sufficient formulation for multiple doses that are metered by the device itself during actuation by the patient.

Dry powder inhalers (DPIs) are inhalers that deliver medication in a dry powder form. DPI medication is delivered by many different designs for inhalation. Examples of DPIs are: *Accuhaler/Discus, Aerohaler, Aerolizer, Clickhaler, Diskhaler, Easyhaler, Handihaler, Novolizer, Pulvinal, Rotadisk, Rotahaler*. The person taking DPI medication must empty the entire dose of medication from the inhaler in one or two breaths. This is sometimes difficult to judge if the device is not designed to be opened to determine that all the medication has been taken.

A spacer/chamber or holding chamber is a device into which the inhaler is sprayed. Many inhaled devices delivering a liquid mist can be used with a spacer/chamber. The mist from the inhaler is sprayed into the spacer/chamber where the large and small particles separate. The large particles stick to the sides of the spacer/chamber while the small particles stay suspended for several seconds. When large particles are inhaled, they only serve to create problems like a sore mouth, hoarse voice and fungal infections in the throat and mouth. Conversely, the small particles stay suspended in the spacer/chamber, allowing time to inhale the fine mist. This device has several advantages over using an MDI without a spacer/chamber e.g. the user no longer has to be as precise in co-ordinating activation of the spray from the canister while inhaling and can first spray the medication into the chamber and then concentrate on inhaling the medication slowly. (177)

### **Appendix 7.9 Pulmonary Rehabilitation (178)**

As indicated in the text in Chapter 7, the table below is of useful in terms of components and outcomes of Pulmonary Rehabilitation Programmes (PRP).

As pulmonary rehabilitation may be beneficial for all patients with COPD and with other chronic respiratory diseases (see examples below) it should be considered as early as possible following diagnosis. In general, symptoms and functional status limitations from pulmonary disease become clinically apparent when one or more of the following are present:

- $FEV_1 \leq 65\%$  of predicted value
- $FVC \leq 65\%$  of predicted value
- Diffusing capacity for carbon monoxide adjusted for haemoglobin  $\leq 65\%$  of predicted
- Resting hypoxemia ( $SpO_2 \leq 90\%$ ).

## Examples of conditions appropriate for pulmonary rehabilitation

### Obstructive Diseases

- COPD (including alpha-1 antitrypsin deficiency)
- Persistent asthma
- Bronchiectasis
- Cystic fibrosis
- Bronchiolitis obliterans

### Restrictive Diseases

- Interstitial lung diseases
- Chest wall diseases

**Table** Core components and Demonstrated Outcomes of pulmonary rehabilitation

|  |
|--|
| <p><b>Core components</b></p> <ul style="list-style-type: none"><li>• Patient assessment of current functional status</li><li>• Exercise training and other therapeutic exercise (aerobic, strength and flexibility training)</li><li>• Education and skills training (such as breathing retraining)</li><li>• Secretion clearance techniques</li><li>• Prevention and management of exacerbations and pulmonary infections</li><li>• Control of irritants and allergens</li><li>• Oxygen systems, proper use, safety and portability</li><li>• Nutritional assessment and intervention if necessary</li><li>• Psycho-social assessment, support, panic control, and professional intervention if necessary</li><li>• Smoking cessation if currently smoking</li><li>• Medication use, management and education</li><li>• Implementation of a home treatment programme follow-up</li></ul> |
| <p><b>Demonstrated Outcomes of Pulmonary Rehabilitation</b></p> <ul style="list-style-type: none"><li>• Reduced respiratory symptoms (dyspnoea, fatigue)</li><li>• Increased exercise performance</li><li>• Increased knowledge about pulmonary disease and self-efficacy in its management</li><li>• Enhanced ability to perform activities of daily living</li><li>• Improved health-related quality of life</li><li>• Improved psycho-social symptoms (reversal of anxiety and depressive symptoms)</li><li>• Reduced exacerbations and use of medical resources</li><li>• Return to work or leisure activities</li></ul>   |

## Appendix 7.10 Oxygen Therapy: Long Term(69, 137)

### a) Long Term Oxygen Therapy

Long term oxygen therapy (LTOT) aims to improve survival in patients with COPD who have severe hypoxaemia ( $\text{PaO}_2 < 8\text{kPa}$ ) as well as reducing the incidence of polycythaemia, reducing the progression of pulmonary hypertension and improving neuro-psychological health. The table below summaries the use of controlled oxygen therapy in those with COPD.

**Table Long term oxygen therapy**

- LTOT is indicated in patients who have a  $\text{PaO}_2$  less than 7.3 kPa when stable or a  $\text{PaO}_2$  greater than 7.3 and less than 8.0 kPa when stable and one of the following:
  - Secondary polycythaemia
  - Nocturnal hypoxia
  - Peripheral oedema
  - Pulmonary hypertension
- Treatment should be for at least 15 hours per day and preferably longer.
- LTOT is usually provided from a fixed oxygen concentrator with plastic piping allowing the patient to use oxygen in their living area and bedroom.
- The need for LTOT should be assessed in
  - All patients with severe airflow obstruction
  - Patients with cyanosis
  - Patients with polycythaemia
  - Patients with peripheral oedema
  - Patients with a raised jugular venous pressure
  - Patients with oxygen saturation  $\leq 92\%$  breathing air
- Access to pulse oximetry is required for patient assessment for LTOT
- Assessment should comprise the measurement of arterial blood gases on 2 occasions at least 3 weeks apart in patients who have a confident diagnosis of COPD, who are receiving optimum medical management and whose COPD is stable.(137)
- Patients should be assessed for LTOT by a respiratory specialist
- Patients receiving LTOT should be reviewed at least once per year by practitioners familiar with LTOT and this review should include pulse oximetry.
- The standard of care for administration of LTOT should be continuous administration with ambulatory capability. (69)
- Exceptions to above point include patients who: (a) are incapable or unwilling to be mobile; (b) require oxygen only during sleep; (c) require oxygen only during exercise; or (d) refuse to use a portable device during ambulation.

**b) Ambulatory Oxygen Therapy:** Ambulatory oxygen is defined as oxygen delivered by equipment than can be carried by most patients. It provides portable oxygen during exercise and activities of daily living. It may be used as part of continuous oxygen therapy in which

case its benefits are those of long term oxygen therapy. The table below summaries the use of ambulatory oxygen therapy in those with COPD.

#### **Table Ambulatory Oxygen**

- It should be considered in those who have exercise desaturation, are shown to have an improvement in exercise capacity and/or dyspnoea and have the motivation to use oxygen. It will allow the patient to leave the house for an appropriate period of time and to exercise without their oxygen saturation falling below 88-92%.
- As with LTOT It should only be prescribed by a specialist who assesses:
  - Extent of desaturation
  - Improvements in exercise capacity with supplemental oxygen
  - Flow rate required to correct desaturation.
- The prescription should always include the source of supplemental oxygen (gas or liquid), method of delivery, duration of use, and flow rate at rest, during exercise, and during sleep.
- Oxygen is usually delivered by nasal prongs, with appropriate inspiratory flow rates of 2-3 litres
- Oxygen concentrator devices are more cost effective than cylinder delivery systems.

Issues around the administration of oxygen during transfer to hospital especially for those already on oxygen and /or in or at risk of respiratory failure are outlined in the table below. All patients on LTOT should have oxygen alert cards.

#### **Table Oxygen therapy during transportation to hospital**

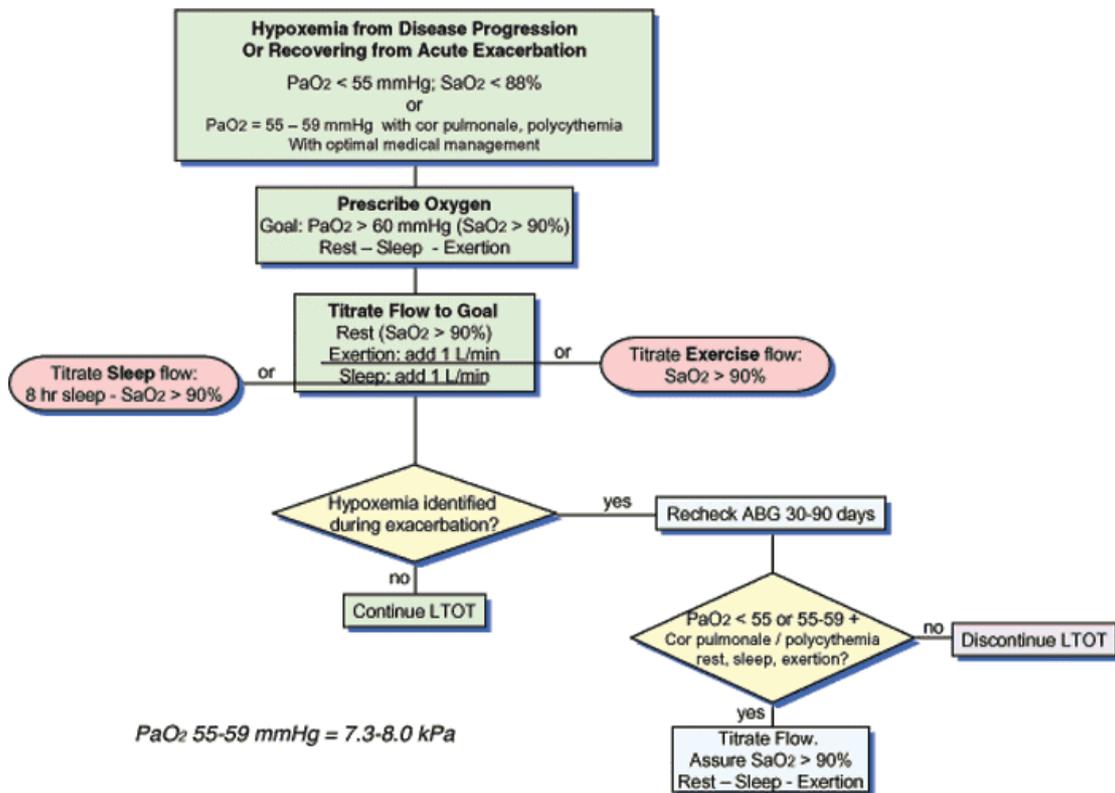
- While being transported to hospital patients should receive controlled oxygen if indicated, 24/28% via (Venturi) mask at flow rates of 2-4 litre / minute.
- During the transfer to hospital the following points should be considered:
  - It is not desirable to exceed an oxygen saturation of 93%.
  - Oxygen therapy should be commenced at approximately 24-28% and titrated upwards if saturation falls below 90% and downwards if the patient becomes drowsy or if the saturation exceeds 93-94%.
  - Patients with known type II respiratory failure need special care, especially if they require a long ambulance journey or if they are given oxygen at home for a prolonged period before the ambulance arrives.
- When the patient arrives at hospital, arterial blood gases should be measured and repeated according to the response to treatment.
- Venturi masks offer more accurate delivery of controlled oxygen than nasal prongs but are less likely to be tolerated by the patient.
- Pulse oximeters should be available to all health care professionals managing

patients with exacerbations of COPD and they should be trained in their use.

- Clinicians should be aware that pulse oximetry gives no information about the  $\text{PCO}_2$  or pH.
- Controlled Oxygen therapy should maintain  $\text{SaO}_2$  between 88% and 92%

The ATS/ERS guidelines include flow chart for prescribing LTOT are shown in the Figure below.(69)

**Figure Prescribing home oxygen therapy(69)**



## Appendix 7.11 Ventilation

### Indications for Non-Invasive Ventilation(15)

- Moderate-to-severe dyspnoea, use of accessory muscles and paradoxical abdominal motion
- Moderate-to-severe acidosis ( $\text{pH} \leq 7.35$ ) and hypercapnia ( $\text{PaCO}_2 > 6.0 \text{ kPa}$ )
- Respiratory frequency  $> 25$  breaths/min

### Indications for Invasive Ventilation(15)

- Severe dyspnoea, use of accessory muscles and paradoxical abdominal motion
- Respiratory frequency  $> 35$  breaths/min
- Life-threatening hypoxaemia ( $\text{PaO}_2 < 5.3 \text{ kPa}$  or  $\text{PaO}_2 / \text{FIO}_2 < 27 \text{ kPa}$ )

- Severe acidosis (pH <7.25) and hypercapnia (PaCO<sub>2</sub> >8.0kPa)
- Respiratory arrest, somnolence and/or impaired mental status
- Cardiovascular complications (hypotension, shock, heart failure)
- Other severe complications (metabolic abnormalities, sepsis, pneumonia, pulmonary embolism)

### **Appendix 7.12 Alternative Care Options**

**Rapid assessment units** aim to identify those patients that can safely be managed at home with additional nursing and medical input rather than being admitted. (179) Such units generally involve a full assessment of the patient at the hospital by a multidisciplinary team and discharge to the community with appropriate support. This may include additional equipment (e.g. a nebuliser and compressor or an oxygen concentrator), nursing supervision from visiting respiratory nurse specialists, and increased social service input. Patients remain under the care of the hospital consultant but GPs are made aware of the fact that they are receiving home care.

**Early discharge schemes** aim to identify patients in hospital who could be discharged before they have fully recovered by providing increased support in their homes.

**Hospital-at-home** is a method of integrated service delivery for the management of acute exacerbations of chronic obstructive pulmonary disease aimed at reducing demand for acute hospital in-patient beds and promoting a patient centred approach through admission avoidance. A Cochrane Review on hospital at home for acute exacerbations of COPD has shown that one in four carefully selected patients presenting to hospital emergency departments with acute exacerbations of chronic obstructive pulmonary disease can be safely and successfully treated at home with support from respiratory nurses. (180) while remaining under the care of the hospital consultant and own GPs.

#### **According to BTS / NICE(137)**

- Hospital-at-home and assisted discharge schemes are safe and effective and should be used as an alternative way of managing patients with exacerbations of COPD who would otherwise need to be admitted or stay in hospital.
- The multi professional team required to operate these schemes should include allied health professionals with experience in managing patients with COPD, and may include nurses, physiotherapists, occupational therapists and generic health workers.
- There are currently insufficient data to make firm recommendations about which patients with an exacerbation are most suitable for hospital-at-home or early discharge.
- Patient selection should depend on the resources available and absence of factors associated with a worse prognosis, e.g. acidosis.

- Patient's preferences about treatment at home or in hospital should be considered.

DRAFT

## **Appendix 8 Chronic Disease Management**

The goal for the well population is:

To protect, promote and improve the health of the population and reduce risk factors to enable people to lead healthier and fulfilled lives with improved quality of life.(26)

For those with a chronic illness such as COPD:

To provide both individual and population based early diagnostics, self management support, education, optimal clinical and social care in the most appropriate setting, stable control of condition, avoidance of complications, improved outcomes and best quality of life.(26)

For those whose chronic illness, COPD, deteriorates:

To provide individuals, population based groups and carers with the knowledge to recognise deterioration, optimal clinical and social care in the most appropriate setting, stable control of condition, rehabilitation and palliative support where appropriate in order to ensure best outcomes and best quality of life.(26)

The World Health Organisation requirements(181) for effective and efficient management of chronic conditions such as COPD are reflected in the DOHC framework document on chronic illness, as outlined below:(24)

- Chronic disease programmes and initiatives should operate within an overall policy framework. This applies to existing initiatives on the development of healthy lifestyles, disease strategies and programmes as well as the development of acute and primary care services.
- The development of intersectoral work to deal with the preventative aspects of chronic disease is a requirement. It will involve an interdepartmental structure through which health improvement actions will be channelled.
- Structure and integrated care for patients with chronic conditions should be provided. Future service models for chronic disease should recognise the need for structured and integrated care and be developed through the service planning process in future years.
- Programmes should be developed for the major diseases in the form of disease management programmes. These programmes should be evidence based, recognise the importance of interdisciplinary work and comprise the total course of the disease.
- Criteria should be established for the definition, diagnosis and stratification of the major chronic diseases. These criteria recognise the pyramid of care where

individuals with chronic conditions can be categorised into three general levels of low, medium and high risk.

- Clinical decision systems such as guidelines/protocols for the management of the major chronic diseases will require development on an incremental basis. It is proposed that these start with cardiovascular disease, stroke, diabetes and COPD.
- Models of shared care should be developed within disease management programmes which describe the nature of tasks between primary care and specialist services. Such models should be developed jointly in advance and clearly set out the roles and responsibilities of those providing healthcare at the specialist and primary care levels.
- Primary healthcare plays a central role in the care of patients with chronic diseases and should be strengthened to meet the needs of patients with chronic conditions.
- Patients should have an agreed management plan whether care is provided in the primary care or by a specialist unit.
- Patients should actively participate in the management of their condition. This will require the development of self-care programmes for patients including skills for self-monitoring, self-treatment, general education and psychological support.
- Clinical information systems should be further developed to support chronic disease management programmes. Many of these will be developed on an incremental basis starting with diabetes and cardiovascular disease. They should use existing information where available and include registration systems which comply with general ICT policy requirements.
- Quality assurance should be an integral part of the disease management programmes for chronic diseases.
- Evidence-based methods and research in chronic disease programmes should be supported.
- Chronic disease programmes should be monitored and evaluated on an ongoing basis. This will require the development of key indicator measures relevant to chronic disease so as to enhance performance.

## **Appendix 9 Implementation Framework: Roles and Responsibilities**

**National Respiratory Steering Group** Roles & Responsibilities: To provide high level direction and guidance on priorities for national respiratory service development and delivery including a National Plan for Respiratory health services:

- To ensure that respiratory services including those for COPD are reflected in the national health service plan and that performance monitoring systems for this are in place
- To promote the use of best practice guidelines and standards
- To facilitate and monitor the implementation of national evidence-based guidelines
- To support a system of quality assurance of respiratory health care including COPD care
- To promote training and educational support, by the health services in partnership with the academic bodies, for health professionals involved in respiratory health care, at all levels, national, regional and local
- To promote the development of ICT to support respiratory health care including COPD, which will include the specification of national minimum data sets
- To identify priorities for relevant national research and to support research and links with academic bodies both national and international
- Through its secretariat to facilitate/source programmes and information specifically tailored to meet the needs of public, patients and HCWs
- The National Steering Group should work with Regional Respiratory Planning Fora and Local Implementation Groups (LIT):
  - to support their work
  - to develop and promote structured and integrated respiratory care in the appropriate setting
  - to develop and enhance respiratory services in both primary and secondary care settings and
  - to improve outcomes and quality of life for patients with respiratory disease including COPD.

**Regional Respiratory Planning Fora:** Roles & Responsibilities: To provide leadership, direction and a regional plan for their geographic area on the development, implementation, monitoring and evaluation of Regional respiratory (including COPD) plans based on regional needs and in line with plan of the National Steering group:

- To facilitate partnership between all disciplines and integration between the various parts of the relevant services including the health services
- To undertake regional health needs assessments to inform the development of local / regional respiratory service plans at all levels of care and to support the primary role

of the GP and primary care team in the overall management of the patients with respiratory disease

- To agree priorities based both on the National plan and the regional needs assessment
- To plan the location and nature of specialist units in accordance with the National Steering Group
- To identify, agree and develop identifiable multi-disciplinary regional clinical networks(s)
- To adapt, implement and audit national standards for respiratory care at regional level including clinical guidelines, care pathways and other quality initiatives
- To provide quarterly updates and annual reports to the National Steering Group
- To support the work of LITs on Respiratory health.

**Local Implementation Teams (LITs)** (or chronic disease LITs): Roles & Responsibilities: To implement the national plans at Local level, following on regional needs assessment.

- to deliver services in accordance with regional needs assessment
- to locally implement the national strategy/service plan and in line with the regional needs assessment
- to ensure integration of primary and secondary care services
- to manage local registers/databases and information technology
- to provide quarterly updates to the Regional Planning Forum.

**Appendix 10 Options for provision of spirometry in community setting**

Option 1

Respiratory scientists from hospital respiratory laboratory outreach to community setting and undertaking spirometry for cohort of patients: where diagnostic uncertainty results could be brought back to respiratory laboratory for interpretation

Option 2

Rapid assessment to respiratory specialist services, including spirometry, in specified situations via eg appointment slots in clinic schedules

Option 3

Protocol for use in primary care for referral / access to spirometry services and interpretation of results; model of tele radiology could be explored

## Appendix 11 Sample Targets

The international literature contains many publications on standards and targets for respiratory services including COPD.(149, 182-185) For all standards and targets, collaboration, integration, and strategic thinking are key factors for success. Plans for improvements in the care of people with COPD/respiratory disease should:

- be part of a broad strategy for respiratory care, which includes hospital, community and primary care
- be based on regional needs and expertise, so that needs of the community are understood and duplication and gaps avoided
- be based on evidence based National Plan
- use and refine existing national and regional data while recognising the limitations of the data
- be realistic about the workforce and focus on the areas where skills need to be developed, while also focusing on developing skills to support self care
- be developed in consultation with people with COPD, so that clinicians can understand how services are experienced, rather than how they are delivered.

The approach to configuring services will vary in different areas, depending on the skills available – hence the need for a national plan but allowing for regional priorities and flexibility as to how to meet these. When considering how best to provide respiratory healthcare services, there is a need to assess the size of the problem, how care is currently provided, develop a service model that best meets local needs, implement the model and then evaluate the success of the approach, making any modifications that are necessary to bring further improvements.

Treatment of respiratory conditions in primary care is predominantly medical, therefore drug budgets can expect to rise as appropriate management is given to more patients at an earlier stage in diagnosis. Pharmaceutical products are part of the solution to rising healthcare costs, not part of the problem. Prompt use of smoking cessation products, together with appropriate support, is one of the most cost-effective of all healthcare interventions. Likewise, effective treatment for COPD that reduces the incidence of acute exacerbations may increase drug budgets but bring savings in the need for costly hospitalisation, as well as benefits to patients in terms of improvements in quality of life. All funding of education and medical interventions for respiratory care is an investment that can offset future health service and societal costs arising from long-term ill health. Pulmonary rehabilitation is currently severely under-resourced, yet this can have long-term benefits by increasing functional ability of patients with COPD.

Below are some sample targets which could be developed for Ireland. Ideally these should reflect the National plan, but does not preclude regional and local initiatives.

### **Goal 1 - establishment of framework for delivery of respiratory services**

**Objective:** establishment of the implementation framework for respiratory disease as a group.

#### **Sample Target(s)**

|  |
|--|
| HSE Management Team  |
| The development of COPD services at national level should be prioritised and reflected in the HSE national service plan.   |
| National Respiratory Steering Group  |
| The National Respiratory Steering Group (which will include COPD) should be established under the HSE Management Team.<br>Target- September 2008.  |
| The National Steering Group should be supported by a dedicated National Office/secretariat: which will be a centre/repository for respiratory health (including COPD).<br>Target- January 2009 |
| Regional Respiratory Planning Fora   |
| Respiratory (including COPD) Planning Fora should be established at HSE Network level.<br>Target- September 2008   |
| Local Implementation Teams (LITs)  |
| The remit, membership and resources of current Local Implementation Teams should be expanded to implement the national respiratory plans at Local level.<br>Target - September 2008            |
| (Alternatively, separate LITs should be established for chronic disease care starting with COPD) to implement the national plans at Local level.<br>Target - September 2008                    |
| Clinical Respiratory Networks  |
| Clinical Networks for respiratory (including COPD) care should be identified and organised at a minimum at HSE Network level.<br>Target January 2009   |

## **Goal 2 Prevent the development and progression of COPD**

**Objective:** Increase population and individual awareness of COPD

### **Sample Target(s)**

- Develop a specific national communication strategy, including media campaign, to increase awareness and knowledge of COPD by X% per year from baseline (to be established)
- etc

**Objective:** Strengthen health promotion efforts relevant to COPD.

### **Sample Target(s)**

- By xxxx, all smokers attending any health service for any reason will be offered smoking cessation services
- By xxxx, 100% of patients admitted to acute hospitals will have a smoking history taken, be advised to stop smoking, offered referral to a smoking cessation programme and advised on nicotine replacement therapy or other pharmacotherapy for nicotine addiction.
- By xxxx, 100% of patients with COPD who smoke, will be advised to stop smoking, offered referral to a smoking cessation programme and advised on nicotine replacement therapy or other pharmacotherapy for nicotine addiction.
- etc

**Objective:** Provide patients and carers with comprehensive, user-friendly information at the time of diagnosis and throughout course of illness

### **Sample Target(s)**

- By xxxx, every patient diagnosed with COPD should have a copy of a national COPD booklet, which includes relevant local and individual information
- etc

**Objective:** Advocate for respiratory health where people live, work and play

### **Sample Target(s)**

- By xxxx, COPD prevalence and mortality should be included as a national indicator of socio-economic inequality by statutory agencies.
- etc

### **Goal 3 Ensure timely access to comprehensive and integrated services in appropriate settings**

**Objective:** Implement structured integrated programmes and services to ensure a comprehensive quality approach for all people with COPD.

#### **Sample Target(s)**

- By xxxx, all primary and secondary health services within each clinical network will have structured integrated care pathways in place for patients with COPD
- By xxxx, all patients with COPD will have timely equitable access to pulmonary rehabilitation programmes
- etc.

**Objective:** Ensure all patients are managed according to evidence based guidelines at all stages of their disease, while also addressing their co-morbid conditions.

#### **Sample Target(s)**

- By xxxx, national clinical guidelines on COPD should be disseminated to all relevant settings and disciplines
- By xxxx, national guidelines on availability, appropriateness of use and administrative procedures for long term oxygen are developed and disseminated
- By xxxx, each primary care and other relevant setting should have access to quality spirometry services
- Etc.

**Objective:** Provide care in the most appropriate setting with all necessary supports according to the patients' needs and severity of illness.

#### **Sample Target(s)**

- By xxxx, there will be a decrease in the number of admissions and bed days used by patients with exacerbations of COPD not requiring ventilatory support by X% from baseline (to be established)
- By xxxx, all hospitals receiving acute medical admissions should have arrangements in place to access NIV 24/7
- Etc.

**Objective:** Facilitate a smooth and seamless patient journey within the required health care settings, and when required, input from other services.

#### **Sample Target(s)**

- By xxxx, each clinical network should have completed a detailed audit of the patient with COPD's journey in their area
- Etc.

#### **Goal 4 Empower patients and carers to actively participate in the management of their condition**

**Objective:** Enable patients to contribute to their own well-being and support them and their carers in developing and maintaining skills to manage COPD.

##### **Sample Target(s)**

- By xxxx, each patient with COPD should have an agreed multidisciplinary care plan
- By xxxx, all patients on oxygen therapy outside the hospital setting should have an oxygen alert card based on a national template
- Etc.

**Objective:** Encourage patients and their carers to retain and develop social networks.

##### **Sample Target(s)**

- By xxxx, all patients with COPD should be able to link with members of a COPD support group, both on an individual and group basis
- Etc.

**Objective:** Provide support for patients to participate in pulmonary rehabilitation.

##### **Sample Target(s)**

- By xxxx, supports should be provided (e.g. transport) so that all patients can participate in pulmonary rehabilitation at a stage in their illness when optimal benefit is possible, and in settings and at times which will maximise their participation
- Etc

#### **Goal 5 Enable health care workers to deliver an evidence-based service**

**Objective:** Develop and deliver an evidence based approach to COPD

##### **Sample Target(s)**

- The regional planning, resourcing and implementation of COPD services should reflect evidence-based guidelines and this should be established via audit by xxxx
- Etc.

**Objective:** Build capacity among all health care staff who care for people with COPD

##### **Sample Target(s)**

- By xxxx, validated national training programmes should be available for spirometry testing and its interpretation
- Etc.

**Objective:** Ensure health care workers have access to the necessary resources to effectively implement best practice

**Sample Target(s)**

- By xxxx, each network will have identified and quantified the necessary resources to effectively implement best practice
- Etc.

**Objective:** Develop information systems to support delivery and evaluation of evidence based services

**Sample Target(s)**

- By xxxx, national performance indicators for COPD services and outcome targets for people with COPD should be specified
- Etc.

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