

### **3. WHY DEVELOP A SERVICE FRAMEWORK FOR RESPIRATORY WELLBEING**

Respiratory disease refers to a wide range of illnesses affecting both the upper and lower respiratory tracts, either acutely or chronically. Patients with respiratory disease often require the expertise of a range of health and social care professionals who have specialised skills in the field of respiratory care. This includes prevention, assessment, diagnosis, treatment, care and rehabilitation.

Respiratory disease was selected as one of the first service frameworks as it continues to be one of the biggest causes of death and disability in Northern Ireland. Death rates from respiratory disease in the UK and Ireland rank among the worst in the European Union.<sup>1</sup>

Using the World Health Organisation International Classification of Disease system (ICD-10),<sup>2</sup> there were 1982 deaths from respiratory disease in Northern Ireland (NI) in 2006.<sup>3</sup> The ICD 10 classification includes lower respiratory tract infections, chronic lower respiratory disease (e.g. COPD), asthma, lung disease due to external agents and other disease affecting the interstitium. It does not include tuberculosis, pulmonary hypertension, sleep apnoea, lung cancer and congenital diseases.

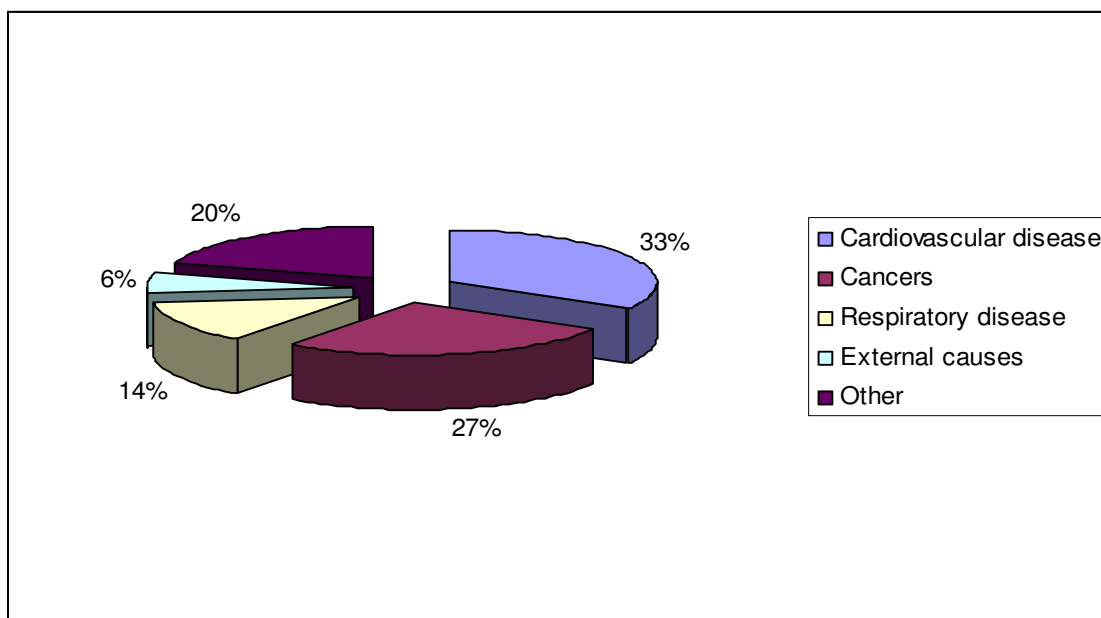
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<sup>1</sup> WHO – European Health for all Database (<http://data.euro.who.int/hfad/>).

<sup>2</sup> World Health Organisation. International Statistical Classification of Disease and Related Health Problems. Tenth Revision. (<http://www.who.int/classifications/apps/icd/icd10online/>)

<sup>3</sup> NISRA. ([www.nisra.gov.uk](http://www.nisra.gov.uk))

**Figure 1: Principal causes of death in Northern Ireland as a percentage of total deaths (2006)**



**Table 1: Principal causes of death in Northern Ireland as a percentage of total deaths (2006)**

Cause	ICD Code	Number of deaths	% of total deaths
Cardiovascular disease	<i>I10-I15, I20-I25, I50, I60-I79</i>	4,878	33.6
Cancers	<i>C00-C97</i>	3,848	26.5
Respiratory disease	<i>J00-J99</i>	1,982	13.6
External causes (accidents, accidental poisoning, suicide, homicide etc)	<i>V00-Y98</i>	853	5.9
Other		2,971	20.4
<i>All causes</i>	<i>A00-Y98</i>	<i>14,532</i>	100

Source: Registrar General Office (NISRA)

As shown above, in 2006, deaths from respiratory disease accounted for almost 14% of all deaths in Northern Ireland. In addition to these 1982 deaths from respiratory disease, there were 850 deaths from cancers of the lung and pleura (ICD 10 C33 – C34) and four deaths from Tuberculosis.

In 2006, just under half (49%) of respiratory deaths were due to a primary diagnosis of infection (Appendix 2). It would be expected that deaths due to infection would increase during years in which there is an epidemic of influenza virus. Just over 30% of respiratory deaths were due to chronic lower respiratory diseases such as COPD. Asthma accounted for just under 2% of all respiratory deaths which, although a small figure, is significant in terms of potential years of life lost. (Potential Years of Life Lost is a measure of premature mortality, representing the number of years of life lost by someone dying before the age of 75).

Although in terms of total numbers, there are more females dying with respiratory diseases in Northern Ireland, when we consider the figures taking account of the age and sex structure of the population, the standardised death rate is higher in males (Appendix 3).

Appendix 4 shows that death rates from respiratory disease are highest in the elderly population. As people are now surviving longer, we would expect the numbers of people dying from respiratory disease to increase. Using the 2002 death rates, and assuming that this rate remains constant over the next 20 years, it is predicted that there will be a 77% increase in the number of deaths from respiratory disease by 2022 (Appendix 5).

## **Morbidity**

As with many conditions, it is very difficult to determine the true incidence and prevalence of respiratory disease in the community. Patients with illnesses which are mild and of short duration often manage their symptoms themselves or take advice from the local pharmacist. Patients with chronic respiratory conditions which are mild to moderate may not consult their doctor, attributing their symptoms to old age or smoking, and assume that nothing can be done to help them.

Respiratory disease prevalence increased by 14% over the period from 1981-1991 in England and Wales, and has shown no signs of improving in the last decade. Respiratory disease is the most commonly reported long term illness in children and young people and the third most commonly reported in adults, after musculoskeletal disorders and heart and circulatory disorders. A study carried out in 1991-2 indicated that patients consult their GP

with respiratory conditions much more frequently than any other group of conditions.<sup>4</sup> GPs continue to see high numbers of patients with respiratory disease as indicated in disease registers which are collated as part of the Quality and Outcomes Framework.

## **What Causes Respiratory Disease?**

The World Health Organisation has identified a number of factors which cause chronic respiratory illness. These are smoking, indoor and outdoor pollution, allergens and occupational risks and vulnerability.<sup>5</sup> Some risk factors are non-modifiable, but others can be modified, thus reducing the risk of respiratory disease.

### **Risk Factors**

#### Non-modifiable Risk Factors

Factors which increase the risk of respiratory disease, but which cannot be modified include hereditary factors such as ethnicity, genetic makeup and increasing age.

#### Modifiable Risk Factors

### **Smoking**

Smoking is the major modifiable risk factor for chronic disease mortality in all European countries.<sup>6</sup> It is estimated to have caused 2,300 deaths in NI per year over the period 1998-2002.<sup>7</sup>

The Northern Ireland Health and Wellbeing Survey (HWBS) 2005/6 estimated the adult smoking prevalence to be 26% (25% in males and 27% in females), with the highest prevalence in the 25-34 year age group. These figures are supported by the 2006/7 Continuous Household Survey which found smoking prevalence to be 25% (25% in men; 26% in women). The latter survey found that 75% of all smokers who took part would like to stop smoking.

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<sup>4</sup> Royal College of General Practitioners. Office of Population Censuses and Surveys and Department of Health. Morbidity Statistics from General Practice, Fourth National Study 1991-92 (<http://www.statistics.gov.uk/STATBASE/Source.asp?vlnk=403&More=Y>)

<sup>5</sup> WHO ([www.who.int/respiratory/en/](http://www.who.int/respiratory/en/))

<sup>6</sup> The Burden of Disease. Lancet 2002;36:1347-60.

<sup>7</sup> Twigg L, Moon, G, Walker S. The smoking epidemic in England. Health Development Agency. (<http://www.nice.org.uk/page.aspx?o=502811>)

Smoking is known to have adverse effects on the unborn child, infants, children, young people and adults. Maternal smoking in pregnancy has been shown to result in impaired lung growth in the developing foetus and may be associated with wheezing in early life.<sup>8</sup>

Smoking is also known to be the main cause of COPD and contributes to the development of other respiratory illnesses.<sup>9</sup> Over the past 20 years there has been a decline in the percentage of men who smoke, but little change in the percentage of women who smoke.

## **Environmental Exposures including Tobacco Smoke**

Exposure to pollutants, both indoors and outdoors, can contribute to the development of respiratory illness or exacerbate existing disease. This includes exposure to environmental tobacco smoke (ETS) in and outside the home, dusts e.g. asbestos, allergens such as the house dust mite, and other pollutants such as enzymes, gases and particles. In many conditions the cause is unknown.<sup>10</sup>

Poor quality air both from external sources and in the home is thought to result in more than 32,000 premature deaths in the UK each year alone.<sup>11</sup> A greater risk of developing respiratory disease (such as chronic bronchitis and COPD) in certain occupations due to prolonged exposure to certain dusts or noxious gases has been well documented.<sup>12,13,14</sup> Smokers who experienced occupational

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<sup>8</sup> Moshhammer H, Hoek G, Luttmann-Gibson H, Neuberger MA, Antova T, Gehring U et al. Parental smoking and lung function in children: an international study. *Am J Respir Crit Care Med* 2006;173: 1255-1263 (<http://171.66.122.149/cgi/content/abstract/173/11/1255>)

<sup>9</sup> British Thoracic Society. Guidelines on the management of COPD. *Thorax* 1997;53(Suppl 5):S1 (<http://www.brit-thoracic.org.uk/ClinicalInformation/COPD/tabid/82/Default.aspx>)

<sup>10</sup> European Respiratory Society. European Lung Foundation. European Lung White Book. The first comprehensive survey on respiratory health in Europe. 2003. (<http://dev.ersnet.org/268-white-book.htm>)

<sup>11</sup> <http://ec.europa.eu/environment/archives/air/cafe/general/keydocs.htm>

<sup>12</sup> Viegi G, Prediletto R, Paoletti P, et al. Respiratory effects of occupational exposure in a general population sample in north Italy. *Am Rev Respir Dis* 1991;143:510–15 ([http://www.occupationalasthma.com/occupational\\_asthma\\_viewreference.aspx?id=868](http://www.occupationalasthma.com/occupational_asthma_viewreference.aspx?id=868))

<sup>13</sup> Fishwick D, Bradshaw LM, D'Souza W, Town I, Armstrong R, Pearce N, and Crane J Chronic bronchitis, shortness of breath, and airway obstruction by occupation in New Zealand, *Am. J. Respir. Crit. Care Med.*, Volume 156, Number 5, November 1997, 1440-1446 (<http://ajrccm.atsjournals.org/cgi/content/abstract/156/5/1440>)

<sup>14</sup> Meldrum M, Rawbone R, Curran AD, Fishwick D The role of occupation in the development of chronic obstructive pulmonary disease (COPD), *Occupational and Environmental Medicine* 2005;62:212-214 (<http://oem.bmj.com/cgi/content/full/62/4/212>)

exposure to pollutants showed an increased prevalence of chronic bronchitis.<sup>15</sup>

The evidence for disease associated with exposure to environmental tobacco smoke is strong.<sup>15</sup> It is known to be associated with respiratory disease as well as its links with increased risks of cancer and heart and circulatory disease. Since April 2007 it is illegal to smoke in enclosed and substantially enclosed workspaces and public areas, to protect people from the effects of second hand smoke as the link between passive smoking and development of a number of diseases has been well established.

### **Social Inequalities**

While respiratory disease affects all sectors of the population, it disproportionately affects those who are disadvantaged. Men in unskilled and manual occupations are 14 times more likely to die from COPD and three times more likely to die from respiratory disease than men in professional occupations.<sup>16</sup>

In 2006/07 in Northern Ireland, hospital admission rates for respiratory disease were 29% higher in the most deprived electoral wards than in NI as a whole. There has been a steady improvement since 2001/02, when the standardised admission rate (SAR) in the most deprived areas was 36% higher than in Northern Ireland as a whole.<sup>17</sup>

Electoral wards with the highest admission rates due to respiratory illness tend to have more single people, more disabled people and more people who would classify themselves as Roman Catholic.

The association with respiratory disease and inequalities is particularly marked when we consider children and young people. Children and young people living in the most deprived areas have

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<sup>15</sup> Action on Smoking and Health. Passive Smoking: A Summary of the Evidence. May 2004. (<http://www.ash.org.uk>)

<sup>16</sup> The Stationery Office, London. Office for National Statistics. Health Inequalities Decennial Supplement. 1997

([http://www.statistics.gov.uk/downloads/theme\\_health/DS15\\_HlthInequls\\_v2.pdf](http://www.statistics.gov.uk/downloads/theme_health/DS15_HlthInequls_v2.pdf))

<sup>17</sup> Health and Social Care Inequalities Monitoring System: Second Update Bulletin 2007 ([http://www.dhsspsni.gov.uk/inequalities\\_monitoring\\_update2.pdf](http://www.dhsspsni.gov.uk/inequalities_monitoring_update2.pdf))

been reported as having admission rates 91% higher than those living in the least deprived areas.<sup>18</sup>

Smoking is one of the major risk markers for respiratory disease and is known to be more common among people from lower socioeconomic groups. A recent survey found 31% unskilled manual groups smoked compared to 15% among professional groups.<sup>19</sup>

The standardised admission rate for respiratory disease in rural areas for 2006/07 was 4% lower than in Northern Ireland generally. In 2001/02 this difference had been 9%, so the gap has narrowed.<sup>20</sup>

### **Physical Activity**

The need to undertake regular physical activity is an ongoing health promotion message which is relevant to everyone trying to maintain good general health. The Northern Ireland Health and Wellbeing Survey 2005/06 found that 23% of all people aged 16 and over can be classified as sedentary i.e. have not performed any moderate level activity lasting 20 minutes on at least one occasion in the last 7 days. Seventy percent of those surveyed indicated they do not take the recommended level of physical activity of at least 30 minute a day on 5 days a week (Figure 2). Physical activity is important in the management of respiratory illness as exercise, specifically tailored to the needs of individuals with respiratory disease, can help prevent muscular atrophy, increase aerobic capacity and overall produce a feeling of general wellbeing.

The literature has focused particularly on physical activity in patients with COPD as part of a pulmonary rehabilitation programme, although people with other types of respiratory disease can also benefit. These programmes have been shown to

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<sup>18</sup> Hawker JI. Social Deprivation and Hospital Admission for Respiratory Infection: An Ecological Study. *Resp Med* 2003 Nov;97(11):1219-24

(<http://www.cababstractsplus.org/google/abstract.asp?AcNo=20043008524>)

<sup>19</sup> Continuous Household Survey 2002-03

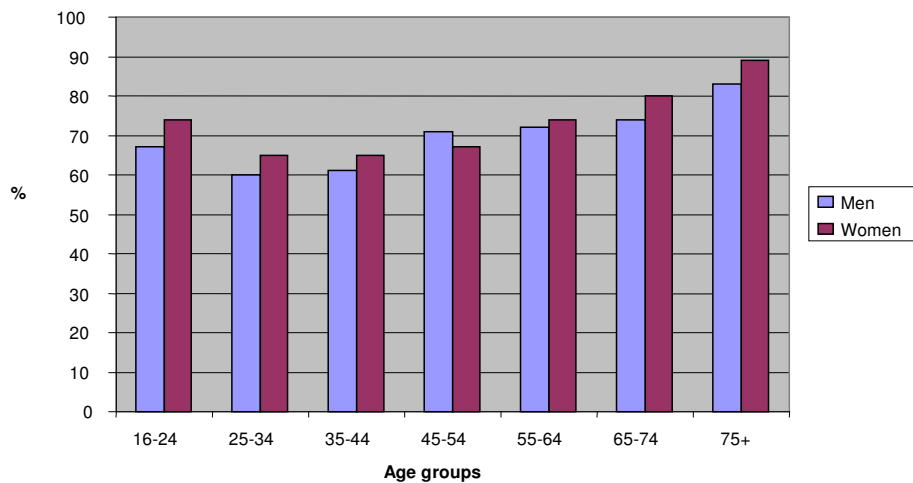
(<http://www.esds.ac.uk/findingData/snDescription.asp?sn=4735>)

<sup>20</sup> Health and Social Care Inequalities Monitoring System: Second Update Bulletin 2007

([http://www.dhsspsni.gov.uk/inequalities\\_monitoring\\_update2.pdf](http://www.dhsspsni.gov.uk/inequalities_monitoring_update2.pdf))

have marked increases in quality of life for participants<sup>21, 22</sup> as well as being cost effective. It must be noted, however, that in pulmonary rehabilitation programmes an holistic approach is taken so that exercise is only one part of a programme which seeks to educate patients about their illness. A recent study, however, has directly linked the benefits of exercise to better outcomes for COPD patients. This study found that regular exercise reduces hospital admission and mortality in COPD patients.<sup>23</sup>

**Figure 2: Below recommended physical activity level by age and sex**



Source: NI Health and Wellbeing Survey 2005/06

## Overweight/Obesity

Respiratory disease has many causes and evidence is scant or inconsistent in determining links between particular foods (or lack of particular foods) in our diet. In general it is recognised that good nutrition helps people fight disease and perhaps improve their symptoms and thus their quality of life.

Studies have indicated an association between adults and children and young people being overweight or obese and obstructive sleep apnoea syndrome (see individual disease sections).

<sup>21</sup>BTS Statement on Pulmonary Rehabilitation (2001) (<http://www.brit-thoracic.org.uk/Portals/0/Clinical%20Information/Pulmonary%20Rehabilitation/Guidelines/Pulmonaryrehab.pdf>)

<sup>22</sup>Ries A, Bauldoff G, Carlin B et al. Pulmonary rehabilitation: Joint ACCP/AACVPR evidence based clinical practice guidelines. Chest 2007;131: 4S-42S. ([http://www.chestjournal.org/content/131/5\\_suppl/4S.full.pdf+html](http://www.chestjournal.org/content/131/5_suppl/4S.full.pdf+html))

Investing for Health, the Public Health Strategy for Northern Ireland<sup>24</sup> has set regional targets to:

- Improve the levels of life expectancy in Northern Ireland towards the levels of the best EU countries, by increasing life expectancy by at least 3 years for men and 2 years for women between 2000 and 2010.
- Halve the gap in life expectancy between those in the fifth most deprived electoral wards and the average life expectancy here for both men and women between 2000 and 2010
- Halt the increase in the levels of obesity in men and women so that by 2010, the proportion of men who are obese is less than 17% and of women less than 20%.

### **Chronic Obstructive Pulmonary Disease (COPD)**

COPD is an umbrella term for people with chronic bronchitis, emphysema, or both. With COPD the airways are narrowed causing obstruction of air flow to the lungs.

COPD is under-diagnosed and consequently prevalence figures are difficult to establish, but it is thought to be in the region of 11% among those over the age of 45 in the United Kingdom. COPD prevalence is increasing in women, but steady in men.<sup>25</sup>

In the Northern Ireland Health and Wellbeing Survey 2005/06, 6% of the respondents aged 55 to 64 years had been told they had COPD, and 7% of the 65 to 74 year olds. A study in NI found the prevalence of COPD among adults aged 40-69 to be 6% and among adults aged 70-80 to be 12%. In this study, using

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<sup>24</sup> J Garcia-Aymerich, P Lange, M Benet, P Schnohr, J M Antó, ,Regular physical activity reduces hospital admission and mortality in chronic obstructive pulmonary disease: a population based cohort study, *Thorax* 2006;61:772-778 (<http://thorax.bmj.com/cgi/content/abstract/61/9/772>)

<sup>24</sup> DHSSPSNI. Investing for Health. March 2002 ([http://www.dhsspsni.gov.uk/show\\_publications?txtid=10415](http://www.dhsspsni.gov.uk/show_publications?txtid=10415))

<sup>25</sup> National Collaborating Centre for Chronic Conditions. Chronic Obstructive Pulmonary Disease. National Clinical Guideline. *Thorax* 2004;59 (Suppl 1):1-232 (<http://thorax.bmj.com/content/vol59/issue90001/>)

<sup>25</sup> Murtagh E, Heaney L, Gingles J, Sheppard R, Kee F, Patterson C, MacMahon J, The prevalence of obstructive lung disease in a general population sample: The NICE COPD study. *Eur J Epidemiol.* 2005;20(5):443-53 (<http://www.ncbi.nlm.nih.gov/pubmed/16080593?dopt=Abstract>)

spirometry as a diagnostic tool, many of those identified as having COPD were unaware that they had this condition.<sup>26</sup>

Under the Quality and Outcomes Framework, practices are now asked to produce registers of patients with COPD. Table 2 indicates that almost 28,000 people were recorded on GP registers in 2006/7 as having COPD.

**Table 2: Number on General Practice Quality and Outcomes Framework COPD Registers by year**

Year	No. on Register	NI Prevalence /1000 pt
2004/05	26,173	14.57
2005/06	26,968	15.01
2006/07	27,815	15.33

Source: Quality and Outcome Frameworks PCAS/DHSSPSNI

## Asthma in Adults and Children and Young People

In Northern Ireland approximately 150,000 people have been diagnosed as having asthma, 115,000 adults and 35,000 children.<sup>27</sup> Between one in four and one in five children have a diagnosis of asthma or have been treated for wheeze.<sup>28</sup> In Britain the general population asthma prevalence is reported to be approximately 6%.<sup>29</sup> A survey of GP Practices in Northern Ireland in October 2004<sup>30</sup> found a similar figure. Since 2004 as part of the Quality and Outcomes Framework, General Practitioners have been compiling disease registers. One of these is a register of patients with asthma, excluding patients with asthma who have been prescribed no asthma-related drugs in the previous 12

<sup>26</sup> Magorrian M et al. Department of Respiratory Medicine, Belfast City Hospital. Unpublished data (2004)

<sup>27</sup> British Thoracic Society. The Burden of Lung Disease. A Statistics Report from the British Thoracic Society. 2006 ([http://www.brit-thoracic.org.uk/Portals/0/Library/BTS%20Publications/burdeon\\_of\\_lung\\_disease2007.pdf](http://www.brit-thoracic.org.uk/Portals/0/Library/BTS%20Publications/burdeon_of_lung_disease2007.pdf)).

<sup>28</sup> Yarnell et al reported by Ulster Thoracic Society, Respiratory Services in Northern Ireland, A Strategy for Development, November 2003.

<sup>29</sup> DRGP 2002-2003 Comparative Analysis Report.

<sup>30</sup> Survey of Respiratory Disease in Primary Care in Northern Ireland – October 2004 (unpublished)

months. The total disease register size and the raw prevalence per 1000 of the population are shown in Table 3. The figures indicate that the prevalence of asthma has remained more or less static at around 5.8%. There is a slight variability from year to year.

In 2002 in depth studies in North and West Belfast and North Down and Ards revealed that 7.2% of 40-69 years olds had asthma, the vast majority (90%) being aware of their diagnosis.<sup>31</sup>

One in ten (10%) of the population aged 16 years and above in NI in a recent population survey stated that they had been diagnosed with asthma at some time in their lives.<sup>32</sup> From an earlier Survey in 2001, over a quarter (26%) of those diagnosed with asthma reported that they had had an asthma attack in the past year. Smokers (13%) and ex-smokers (11%) were more likely to have been diagnosed with asthma than those who never smoked (9%).<sup>33</sup>

**Table 3: Number on General Practice Quality and Outcomes Framework Asthma Registers by year**

Year	No. on Register	NI Prevalence /1000 pt
2004/05	102,520	57.08
2005/06	104,609	58.21
2006/07	104,868	57.80

Source: Quality and Outcome Frameworks PCAS/DHSSPSNI

<sup>31</sup> Murtagh E, Heaney L, Gingles J, Sheppard R, Kee F, Patterson C, MacMahon J, The prevalence of obstructive lung disease in a general population sample: The NICE COPD study. Eur J Epidemiol. 2005;20(5):443-53 (<http://www.ncbi.nlm.nih.gov/pubmed/16080593?dopt=Abstract>)

<sup>32</sup> Northern Ireland Health and Social Wellbeing Survey 2005/06 ([http://www.dhsspsni.gov.uk/hwb\\_topline\\_bulletin.pdf](http://www.dhsspsni.gov.uk/hwb_topline_bulletin.pdf))

<sup>33</sup> Northern Ireland Health and Social Wellbeing Survey 2001

## **Community Acquired Pneumonia in Adults and Children and Young People**

It is estimated that between 44-84 cases per 1000 adult population per year present to their GP with symptoms of lower respiratory tract infection<sup>34</sup> - in other words a GP is likely to see 69-133 cases of lower respiratory tract infection each year.

It is estimated that 14,000 adults in NI are treated for community acquired pneumonia (CAP) each year.<sup>35</sup>

Around 8,000 children under the age of fourteen in NI are likely to develop CAP each year<sup>36</sup> (each GP will treat about 8 children with pneumonia). The incidence is twice as high among children aged under five as in older children.

## **Obstructive Sleep Apnoea / Hypopnoea Syndrome in Adults**

Obstructive sleep apnoea / hypopnoea syndrome (OSAHS) occurs when the upper airway collapses and for brief periods obstructs breathing and disrupts sleep. One consequence of this is excessive daytime sleepiness, which is a major risk factor for serious road traffic accidents. Sleep apnoea is considerably under diagnosed due to lack of awareness among the public and health care professionals.

In 2003<sup>37</sup> the review of studies of the prevalence of OSAHS showed variation from 0.3 – 4% of men aged 30-65. A conservative estimate of 1-2% was used for men and 0.5-1% for women. These figures were based on studies from the early 1990s.

A current prevalence of 2-4% for men and 1-2% for women is generally considered to be the current estimate of OSAHS, but is

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<sup>34</sup> Scottish Intercollegiate Guideline Network (SIGN) guidelines on Community Management of Lower Respiratory Tract Infection in Adults 2002 (<http://www.sign.ac.uk/guidelines/fulltext/59/index.html>)

<sup>35</sup> British Thoracic Society (BTS) Guidelines for the management of community acquired pneumonia in adults, 2001 (Update in 2004 to be read in conjunction with 2001 guidelines).

<sup>36</sup> British Thoracic Society (BTS) Guidelines for the management of community acquired pneumonia in children, 2002.

<sup>37</sup> Scottish Intercollegiate Guidelines Network. Management of Obstructive Sleep Apnoea/Hypopnoea Syndrome in Adults. June 2003. ISBN 1 899893 33 4. (<http://www.sign.ac.uk/guidelines/fulltext/73/index.html>)

probably still an underestimate. One percent of men may have severe OSAHS.<sup>38</sup> Based on these percentages, there are an estimated 11,000 - 22,000 people in Northern Ireland, aged between 30–64, with OSAHS.

Some of the reported differences in prevalence are due to different classification criteria, but worryingly a longitudinal study (published in 2000) has shown that a 10% increase in weight predicated a 6-fold increase in the odds of developing moderate to severe Sleep Disordered Breathing (SDB).<sup>39</sup>

A study in Northern Ireland<sup>40</sup> in 2001 showed that 6.6% of men reported loud snoring and excessive daytime sleepiness.

### **Obstructive Sleep Apnoea Syndrome (OSAS) in Children and Young People**

Obstructive Sleep Apnoea Syndrome (OSAS) is a disorder in children characterised by repetitive episodes of upper airway obstruction, intermittent hypoxaemia and hypercapnoea, and snoring. Limited epidemiological data suggest that the disorder affects up to 3% of 'middle-aged' children and may be higher in those 3-6 years of age (13%). Childhood OSA is thus relatively common and may cause significant morbidity. Most children snore at some time but not all have OSA.

The causes differ from those in adults and are as follows:

Upper airways physical narrowing:

- adenotonsillar hypertrophy
- craniofacial structural abnormalities.

Abnormalities of upper airway tone:

- Down's Syndrome.

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<sup>38</sup> NICE Technology Appraisal. Sleep apnoea – continuous positive pressure (CPAP). March 2008 (<http://www.nice.org.uk/Guidance/TA139>)

<sup>39</sup> Peppard PE, Young T, Palta M, Dempsey J, Skatrud J. Longitudinal study of moderate weight change and sleep disordered breathing. JAMA 2000; 284: 3015-21. ([http://jama.ama-assn.org/cgi/content/abstract/284/23/3015?ijkey=f180880a402a364a3ee01fec99a564bda8b0cc10&keytype2=tf\\_ipsecsha](http://jama.ama-assn.org/cgi/content/abstract/284/23/3015?ijkey=f180880a402a364a3ee01fec99a564bda8b0cc10&keytype2=tf_ipsecsha))

<sup>40</sup> Nugent AM, Gleadhill I, McCrum E, Patterson CC, Evans A, MacMahon J. Sleep complaints and risk factors for excessive day time sleepiness in adult males in Northern Ireland. J Sleep Res 2001; 10: 69-74. (<http://www.blackwell-synergy.com/doi/pdf/10.1046/j.1365-2869.2001.00226.x?cookieSet=1>)

Obesity:

- common obesity in childhood is on the rise in Northern Ireland and likely will be associated with more cases of OSA in the future
- syndromes associated with morbid obesity – Prader Willi syndrome, post craniopharyngioma.

OSA affects 1-2% of children and is known to have a detrimental effect on affected their academic performance.<sup>41</sup>

### **Long Term Ventilation in Children and Young People**

Long term ventilation (LTV) has an established track record in patients with ventilatory failure. There are currently 27 children on LTV support in N Ireland. The numbers are likely to increase as the benefits of this treatment are realised for children with neuromuscular disease (NMD).<sup>42</sup>

In some LTV involves 24 hour respiratory support (e.g. spinal cord injuries) while in the majority the goal is to treat nocturnal hypoventilation and thereby improve day time quality of life (for example, for children with NMD).

Respiratory insufficiency is the most common cause of early death in children and adolescents with NMD. In the last decade non invasive ventilation (NIV) has considerably extended survival in children with these conditions and simultaneously improved quality of life. Nocturnal non invasive ventilation (NIV) is often beneficial before scoliosis surgery in children with Duchenne Muscular Dystrophy (DMD) or Spinal Muscular Atrophy (SMA).

There are two main groups of children and young people who may require LTV

- children surviving a period in paediatric intensive care e.g. spinal injury
- children with chronic and generative disease such as:
  - Neuromuscular diseases e.g. DMD, SMA and other NMDs

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<sup>41</sup> Brunetti et al. Prevalence of Obstructive Sleep Apnoea Syndrome in a cohort of 1207 children in Southern Italy. Chest 2001;120:1930-5. (<http://www.chestjournal.org/cgi/content/full/120/6/1930>)

<sup>42</sup> Simonds AK, Recent advances in respiratory care for neuromuscular disease, Chest 130: 1879-1886 (<http://www.chestjournal.org/cgi/content/full/130/6/1879>)

- Skeletal disorders e.g. kyphoscoliosis and craniofacial deformities
- Rarely, neonatal chronic lung disease, OSAS.

## **Cystic Fibrosis**

Cystic fibrosis (CF) affects the internal organs, especially the lungs and digestive system, by clogging them with thick sticky mucus. This makes it hard to breathe and digest food.<sup>43</sup>

CF is the most common severe autosomal recessive genetic disorder in North West European populations. It is particularly prevalent in Northern Ireland because of a high gene carriage rate (around 1/20 of the population). CF is the UK's most common life threatening inherited disease affecting over 8,000 people.

There are currently 420 people diagnosed with CF in Northern Ireland and all attend the adult and paediatric CF centres in Belfast. CF used to be considered a condition of children, but the prognosis has improved year on year and there are now slightly more adults than children and young people with CF in Northern Ireland. Median survival for CF is now of the order of 37-38 years, though median age at death remains in the late 20s. This is accounted for by early diagnosis due to neonatal screening and centralised care with specialist multidisciplinary teams.

## **Bronchiectasis**

Bronchiectasis is caused by a number of underlying conditions including cystic fibrosis, immunodeficiency and primary ciliary dyskinesia. A number of other conditions such as rheumatoid arthritis, inflammatory bowel disease and alpha 1 antitrypsin deficiency are associated with bronchiectasis.

Bronchiectasis is a common long term medical condition resulting in considerable morbidity and frequent admissions to hospital. The exact prevalence is unclear, but incidence increases with age. There are likely to be around 5,000 people in Northern Ireland with bronchiectasis resulting in 300-500 hospital admissions annually.

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<sup>43</sup> Cystic Fibrosis Trust (<http://www.cftrust.org.uk>)

Bronchiectasis is probably grossly under diagnosed, as high resolution CT scanning is the only accurate way to make a diagnosis.

## **Tuberculosis**

The incidence of tuberculosis (TB) in Northern Ireland remains low (3.5 cases per 100,000 population). In 2006, there were 61 cases of TB notified here, of which 42 (69%) affected the lungs.<sup>44</sup> Some groups within the population are at higher risk of developing TB than others, for example those who are immunosuppressed, the disadvantaged including the homeless, those with alcohol problems and those from certain ethnic backgrounds, particularly if born in countries where TB is endemic.<sup>45</sup>

## **Interstitial Lung Disease (ILD)**

Interstitial lung diseases (ILD) encompass a large range of disorders (over 200), affecting the functional part of the lung or the 'lung parenchyma.' There is no universally agreed classification of the disorders, but they all present similarly with increasing shortness of breath and widespread shadowing on a chest x-ray. The most frequently occurring are idiopathic pulmonary fibrosis (IPF) and sarcoidosis. ILD also includes environmental lung diseases such as extrinsic allergic alveolitis and asbestosis.

Pulmonary fibrosis is a scarring of the lung tissue, resulting in the lungs losing the ability to transfer oxygen into the bloodstream as effectively. The term idiopathic refers to the fact that the cause is unknown. Around 55 new cases of idiopathic pulmonary fibrosis (IPF) are expected each year in Northern Ireland. A recent UK wide study, using information from 255 GP practices from 1991 to 2003, estimated the crude incidence rate of IPF in Northern Ireland as 3.26 per 100,000 person-years, with more cases in women than in men<sup>46</sup>. The incidence of IPF in the UK as a whole increased with age (rate of 0.5 per 100,000 person-years in the under 55 age group increasing to 25 per 100,000 person-years in the 75-84 year

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<sup>44</sup> Communicable Disease Surveillance Centre Northern Ireland (<http://www.cdscni.org.uk>)

<sup>45</sup> Davies P, Grange J Factors affecting susceptibility and resistance to tuberculosis. *Thorax* 2001;56 (Suppl 2):ii23-ii29 ([http://thorax.bmj.com/cgi/content/extract/56/suppl\\_2/ii23](http://thorax.bmj.com/cgi/content/extract/56/suppl_2/ii23))

<sup>46</sup> J Gribbin, RB Hubbard, I Lejeune, CJP Smyth, J West, LJ Tata. Incidence and mortality of idiopathic pulmonary fibrosis and sarcoidosis in the UK. *Thorax* 2006; **61**: 980-985 (<http://thorax.bmj.com/cgi/content/abstract/61/11/980>)

age group). During the period of the study the incidence increased in all age groups by 11% per annum, which can not be explained by the aging population. The median survival of patients with a diagnosis of IPF was 3.9 years.

Sarcoidosis is an immune system disorder characterized by non-caseating granulomas (inflammatory nodules). Again the cause is unknown. The expected number of new cases of sarcoidosis in Northern Ireland each year is 121. From the same study, the crude incidence rate of sarcoidosis in Northern Ireland was estimated as 7.71 per 100,000 person-years. The rates were similar in males and females, with the highest incidence in the 25-35 age group. The crude mortality rate was 14 per 1000 person-years, which was about double that of a comparison cohort (matched general practice population).

### **The Impact of Respiratory Disease on Health and Social Care Services**

Care of patients with respiratory diseases is a major contributor to the overall work and expenditure of health and social services. Acute upper respiratory tract infections are the most common reason for GP attendance among children and rank in the top five reasons for consultation for all age groups.<sup>47</sup> In 2006 community drug prescribing costs, excluding vaccination costs for respiratory disease were in the region of £37.7m.<sup>48</sup> As well as the cost to the health and social care services, patients themselves often pay for prescription charges, equipment, and travel expenses.

In 2005/06 there were 29,724 admissions to hospital for respiratory conditions in Northern Ireland.<sup>49</sup> Twenty four percent of respiratory admissions were for chronic lower respiratory diseases such as COPD or asthma. Appendix 6 provides further details of admissions.

In 2005/06, a total of 196,761 bed-days were used for patients with respiratory disease representing 9% of all bed-days. These figures would be significantly higher if a wider definition of respiratory disease were to be used. Over 46% of respiratory admissions and almost 53% of respiratory bed days were related to infection.

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<sup>47</sup> Scottish Health Statistics (<http://www.isdscotland.org>)

<sup>48</sup> Central Services Agency (<http://www.centalservicesagency.com>)

<sup>49</sup> DHSSPSNI (<http://www.dhsspsni.gov.uk>)

Some of these admissions required endotracheal intubation and ventilation in intensive care.

In 2005/06, the average length of stay for patients with respiratory illness was 6.6 days but there was considerable variation depending on the nature of the illness reflecting the age profiles of the patients affected. Older people tend to have other medical problems and require more support, both during admission and after discharge, which may cause longer stays. Short stays were associated with conditions such as upper respiratory tract infections (1.7 days). The longest stays were associated with lung diseases due to external causes such as occupational lung disease (19.3 days).

Since the population is ageing and respiratory disease is more common in the elderly, it is predicted that by 2025 there will be a 23% increase in admissions, if current admission patterns remain constant (Appendix 7).

## **Social Consequences and Economic Costs**

The cost to the patient and carer in terms of suffering and disability associated with respiratory disease is great. Children and young people with undiagnosed or poorly controlled respiratory conditions miss significant days from school placing them at risk of not achieving their full academic potential. Around a quarter of children and young people with asthma in Northern Ireland report at least moderate disruption to their daily activities.<sup>50</sup> Respiratory illness in adults affects quality of life. They may be unable to participate in employment or leisure and social activities and risk becoming socially isolated (Appendix 8).

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<sup>50</sup> Yarnell et al. Smoking, atopy and certain fluffy pets are major determinants of respiratory symptoms in children: The International Study of Asthma and Allergies in Childhood Study (Ireland). Clin Exp Allergy 2003;33:96-100.  
(<http://www.ingentaconnect.com/content/bsc/cea/2003/00000033/00000001/art00016;jsessionid=1qugszjnk719b.alexandra?format=print&crawler=true>)