The battle for breath

– the impact of lung disease in the UK

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Foreword

By Professor Sir Michael Marmot

Breathing is something we all do, day in, day out, every day of our lives. It is so innate that most of us rarely stop to think about it. We think less of breathing than of the life it sustains.

For millions of people across the UK, breathing is something they have *had* to think about. These are people for whom the beautiful but delicate organs with which we breathe – the lungs – do not work as they should.

One in five of us in the UK has been diagnosed with a lung disease. Every year, over half a million more people are told they have a lung disease.

Lung disease continues to be a major factor in health inequalities. Someone from the most deprived section of society is two-and-a-half times more likely to have COPD, and nearly twice as likely to develop lung cancer, as someone from the least deprived section of society.

Overall, the burden that lung disease places on our nation's health and health services is immense – on a par with non-respiratory cancer and heart disease. Yet the amount of resources and attention invested in tackling lung disease trails behind these other disease areas.

These are among the findings and conclusions presented in *The battle for breath* as part of the most comprehensive overview of lung disease in the UK currently available.

While some of the findings in this report are surprising and change our view of lung disease, much is also disappointingly familiar. Perhaps most tellingly, during a period in which the number of people dying from heart disease in the UK has tumbled, the number of people dying from lung disease has barely changed since the last major report of this kind was published ten years ago.

I hope that ten years from now, the situation will be different. The data and analyses contained within this report provide much of the statistical information – and the ethical rationale – for action. But the academics, health care professionals and charitable organisations working in respiratory disease need the support and commitment of government and policy-makers to bring about the step change that's needed.

We've seen over recent years how concerted efforts to tackle cancer and cardiovascular disease can yield real progress. It's time now to breathe new life into the fight against lung disease.

The battle for breath: the impact of lung disease in the UK

Executive summary

The British Lung Foundation funded a three-year epidemiological research project: *The respiratory health of the nation*. This report presents the results. It details the overall extent and impact of lung disease across the UK. It also takes a closer look at the impact of 15 major lung conditions.

The data collected here and on our website are an invaluable resource for policy-makers, researchers, health care providers and professionals, and the commercial health care sector, patients and patient groups. They can inform much-needed strategies to improve lung health and lung disease outcomes in the UK. They can also be used as a baseline for measuring the success of these strategies.

Key findings

Lung disease is one of the three biggest killer disease areas in the UK, alongside heart disease and non-respiratory cancers. It kills 115,000 people each year, the equivalent of one person every five minutes. These mortality figures are roughly the same as those reported by the British Thoracic Society a decade ago. In comparison, the number of deaths from heart disease went down by 15% from 2008 to 2012.

The UK has the fourth highest mortality rate from lung disease in Europe.

Around 12 million people, one in five of the UK population, have been diagnosed with lung disease. We also found some diseases, such as asthma and bronchiectasis, to be more common than previously thought.

There are 550,000 new diagnoses of lung disease each year, equivalent to 1,500 a day. This is nearly 80% higher than the number of diagnoses for non-respiratory cancers.

Lung disease places a huge burden on health care services. It accounts for over 700,000 hospital admissions and over 6.1 million hospital bed days in the UK each year. Only heart disease accounts for more. Better diagnosis and disease management would reduce this burden, particularly on emergency care.

While lung disease is more common in adults, it accounts for 11% of deaths in children under 15. It is also responsible for around 9% of all child hospital admissions.

Chronic obstructive pulmonary disease (COPD) and lung cancer kill more people each year than any other lung disease. Smoking is the most common cause of both diseases. Rates of, and deaths from, smoking-related lung disease are highest in the north of England and Scotland. As a result, mortality from lung disease as a whole is also highest in these areas.

Lung disease is a major factor in widening health inequalities in this country. There is a correlation between some of the most common lung diseases – COPD, asthma and lung cancer – and social deprivation. For COPD and lung cancer, this can be explained in large part by higher rates of smoking, as well as greater exposure to air pollution and workplace dusts and chemicals. For asthma, the link with social deprivation needs further study. In all cases, more, better-targeted interventions could reduce these inequalities and the prevalence of lung disease overall.

We also found certain diseases, such as bronchiectasis and sarcoidosis, to be more common in the least deprived communities. This is counterintuitive and requires more research. However, it may reflect better diagnosis and longer survival rates among these groups, making it another factor in widening health inequalities.

Recommendations

This report confirms that the impact lung disease has on the nation's health and health services is broadly the same as non-respiratory cancer or cardiovascular disease. Yet despite this similar burden, lung disease has not received a similar level of attention and investment, and mortality has stagnated. Lung disease needs to receive equal priority to these other disease areas if we are to see improvements in outcomes.

We are calling for policy-makers to take action in six key areas:

1. Establish taskforces for lung health in England and Scotland, to produce new five year strategies for tackling lung disease*
2. Make respiratory one of the mandated priority areas for strategic clinical networks in England, to integrate care better and reduce lung health inequalities†
3. Establish a national respiratory intelligence network and improve data recording, collection and analysis across the UK
4. Put respiratory disease research funding on an equal footing with cancer and cardiovascular research funding
5. Update the NHS Health Check in England, and invest in awareness campaigns, evidence-based screening and greater diagnostic capacity throughout the UK
6. Invest in prevention, including tackling smoking, obesity, physical inactivity and air pollution

* Northern Ireland already has an taskforce equivalent; Wales already has a delivery plan for respiratory disease
† Similar bodies already exist in Wales, Scotland and Northern Ireland

The battle for breath – **the key findings from our report**

The number of people affected by lung disease

- Around one in five of the UK population (12 million people) has received a diagnosis of lung disease in their lifetime.
- Around 550,000 people are diagnosed with lung disease in the UK every year. If this were spread evenly throughout the year, then at least one person would be diagnosed with lung disease every minute of every day.
- Some lung diseases are more common than UK public health bodies suggest. For instance:
  - Over 40% more people are living with chronic obstructive pulmonary disease (COPD) than reported by the Department of Health
  - Idiopathic pulmonary fibrosis (IPF) is more than twice as common as National Institute for Health and Clinical Excellence (NICE) states in its official guidance
  - Bronchiectasis is over four times more common than NHS figures suggest.

The number of people dying from lung disease

- Lung disease kills around 115,000 people every year in the UK – equivalent to one every five minutes.
- Only three European countries – Denmark, Romania and Hungary – have a higher lung disease mortality rate than the UK.
- Alongside heart disease and non-respiratory cancer, lung disease is one of the UK's three biggest killers. And while mortality from heart disease and many non-respiratory cancers is falling, the number of people killed each year by lung disease is staying the same.
- There are three lung diseases – lung cancer, COPD and pneumonia – in the top six most common causes of death in the UK.

The impact of lung disease on society and health services

- Lung disease is strongly linked to social deprivation and health inequalities. If you are from the most socially deprived 20% of the population, you are two-and-a-half times more likely to have COPD and nearly twice as likely to develop lung cancer compared with someone from the least deprived group in society.

- Lung disease places a huge burden on health services. It is responsible for over 700,000 hospital admissions and more than 6.1 million hospital bed days in the UK each year.

Introduction and methodology

Background to the research project

This report presents data resulting from a three-year epidemiological research project – *The respiratory health of the nation* – funded by the British Lung Foundation. The project aimed to compile a comprehensive overview of the extent and impact of lung disease across the UK. This has not been done since 2006, when the British Thoracic Society published the 2nd edition of its report *The burden of lung disease*.

The research was carried out between 2013 and 2016. The research project team was led by Professor David Strachan, Professor of Epidemiology and Director of the Population Health Research Institute at St George's, University of London. Professor Strachan was supported by a team of epidemiologists: Ms Ramyani Gupta and Ms Elizabeth Limb at St George's; Professor Richard Hubbard, Dr Jack Gibson and Dr Laila Tata at the University of Nottingham; Professor Peter Burney, Professor Deborah Jarvis, Professor Paul Cullinan, Dr Anna Hansell, Dr Ioannis Bakolis and Dr Rebecca Ghosh at Imperial College London, and Professor Aziz Sheikh at the University of Edinburgh.

BLF research and policy teams extracted data summaries and key points. They did this with support and advice from the epidemiologists from the research project team who compiled the data, and from leading clinicians in each of the disease areas covered.

Who this report is for

The aim of this report is to provide the information needed to help improve the respiratory health of the nation. These data and analyses should inform the development of strategies designed to reduce the impact of lung disease on the UK's health. They can also be used as baseline data to measure the effectiveness of these strategies. The conclusions and recommendations section of this report has outlined some of the approaches that should be included in these strategies.

The report is therefore an invaluable resource for:

- policy-makers
- researchers
- health care providers and professionals
- the commercial health care sector

It is also useful for anyone else looking for facts and information about lung disease and specific conditions. This includes media professionals and people living with lung disease.

Data sources used in the research project

The research project team used various data sources to compile an up-to-date overview of lung disease. They also looked closely at 15 major lung conditions. They compiled data relating to:

- prevalence (the number of people who are living with or have previously been diagnosed with the disease)
- incidence (the number of new diagnoses made each year)
- mortality (the number of people who die from lung disease)
- impact on hospital services
- gender
- age
- regional variation
- social deprivation
- international comparison

Data relating to people of all ages were compiled. Overall, the data provide the most accurate picture available of the respiratory health of the nation. However, the data sources used impose certain limitations on the strength of the conclusions that can be drawn.

The sources used and their limitations are detailed here.

Prevalence and incidence data, including data relating to age and gender

The research project team used The Health Improvement Network (THIN) database records for 2004-13 to estimate prevalence and incidence data. These 12.6 million patient records from 591 GP surgeries represent a sample of approximately 5% of the population.

Using population estimates, the team scaled up THIN data to produce estimated total figures for the UK population. They also calculated breakdowns by gender, age group, region and levels of deprivation. The regions were based on former Strategic Health Authority areas in England, Wales, Scotland and Northern Ireland.

The research project team used a process of direct standardisation to estimate the number of people newly or ever diagnosed with each condition. First, they looked at the annual rates recorded by THIN, broken down by age group, gender and region. They then multiplied these by the total number of the UK population in each subgroup in that year (using mid-year population estimates from the Office of National Statistics). Finally, they added these together to produce overall estimates.

For some lung conditions, such as pneumonia, it is possible for a single person to be diagnosed with the disease more than once. For instance, someone might be diagnosed, recover, then be diagnosed again at a later date. For these conditions, incidence and prevalence were recorded as the number of individual persons diagnosed, rather than the number of separate episodes of the disease. This was to make the data comparable with long-term lung diseases, with which someone can only be diagnosed once.

Limitations

THIN data are commonly accepted as the most accurate available when looking at prevalence and incidence of disease presenting to GPs. But there are limitations in using these data related to the degree of accuracy of the source data, and possible errors when estimating overall figures. Although these do not in any way invalidate the data, they should be borne in mind when considering the figures.

Limitations to the accuracy of the source data:

- The validity of the estimates depends on how accurately GPs have recorded and coded diagnoses.
- It is also reliant on hospitals feeding data back to GPs when patients are diagnosed in secondary care. Hospital feedback is generally reliable. However, the figures may be slightly underestimated for diseases like pneumonia, pneumothorax and pulmonary embolism that are diagnosed and managed during a single hospital stay. Hospitals may not feedback all such instances to be recorded in GP data.
- Some of the diagnoses included here for conditions like mesothelioma, respiratory tuberculosis (TB) and sarcoidosis may relate to organs other than the lungs. This is because there is no reliable way to separate them out in the GP data. However, such errors are likely to be small.

- Some incidence trends may be due to changes in the way health care professionals coded data over the period concerned. For instance, use of new codes may steadily increase as GPs get used to them, before levelling off at a certain rate of use. This may give the illusion that prevalence is increasing when it is just use of a particular code that it is increasing. For this reason, data compiled before 2008 were analysed with extreme caution. Use of coding from 2008 onwards was considered more consistent, but some variation in prevalence and incidence, particularly among less common conditions, may still result from changes in coding use rather than reflecting genuine changes in disease rates.

- Similarly, a number of different codes can be used to record diseases like idiopathic pulmonary fibrosis (IPF). The research project team, with advice from clinicians and the BLF's internal research team, used codings they considered to offer the most accurate picture of true incidence and prevalence.

Limitations to the estimates of overall figures:

- The 5% of the UK population represented by THIN data is from a sample of GP practices, rather than all practices. There is a possibility of error once these figures are extrapolated to apply to the UK as a whole.

- The researchers either omitted or treated with caution data from 2013. Many practices submitted their last data set in mid-2013, and the researchers applied their extrapolation to provide a full-year estimate. This introduces the possibility of error in 2013 data.

- Regarding estimates of the overall number of people newly or ever diagnosed with each condition:

  - For rare diseases these estimates should be treated with caution. This is because they are based on age-, gender- or region-specific subgroup estimates of disease rates in each year. The number of diagnoses in some subgroups may be very small. So they could be subject to a high level of random variation from year to year.

  - Changes in absolute number estimates over time are produced by a combination of changes in underlying rates of disease, and changes in the structure and size of the UK population. So an increase in the incidence of a condition may indicate that it is becoming more common. Or that the section of the population most affected by the disease could have expanded. It could also reflect a combination of the two, or other factors such as improvements in diagnosis.

Mortality data

The research project team obtained mortality data from the Office for National Statistics for England and Wales, the General Register Office for Scotland and the Northern Ireland Statistics and Research Agency.

Numbers of deaths were totalled over the five years from 2008 to 2012. Age-standardised mortality ratios by region were calculated for each condition over this five-year period, separately for males and females.

Using age-standardisation takes the ages of people within a population into account when comparing rates of disease. This is so that, for instance, comparisons of the number of people dying with a condition are not unduly influenced by the fact that there might be a larger number of older people in a particular population at that time.

Often the underlying cause of a person's death is different from the disease that eventually killed them. For instance, someone may have been admitted to hospital and made vulnerable to infection by COPD, but eventually killed by pneumonia. In these instances, our figures comply with World Health Organisation (WHO) international mortality coding rules under which the underlying cause of death is recorded.

Limitations

These statistics relate to the underlying cause of death, coded according to internationally agreed criteria. This means they more accurately reflect the numbers of people dying *from* lung disease than the numbers dying *with* lung disease. The death of those *with* lung disease may be certified to other causes.

Comorbid lung disease could shorten lifespan. It impairs the chance of surviving an acute non-respiratory illness, such as heart attack or stroke.

Impact on hospital services

The research project team used the WHO Europe Hospital Morbidity Database (HMDB) to analyse total hospital admissions and bed days. This uses the International Classification of Diseases (ICD-10) coding. The latest reliable available data were from 2011.

Regional variations in hospital admissions were produced by looking at age-standardised hospital admissions ratios for common lung diseases. They are based on emergency admissions only, which accounted for 94% of UK hospital admissions for lung disease in 2011.

Limitations

These statistics relate to the main reason for admission to hospital. As with mortality data, the true impact of comorbid lung diseases may be underestimated.

Regional breakdown

THIN data were used to calculate regional breakdowns, standardised by age, gender and deprivation.

Regional variations in emergency hospital admissions are also provided. The sources for these were English hospital episodes statistics data from the Health and Social Care Information Centre (HSCIC), NHS Wales Informatics Services, the Information Services Division (ISD) Scotland and the Department of Health, Social Services and Public Safety (DHSSPS) Northern Ireland.

Limitations

Hospital admissions data were supplied by different agencies for England, Scotland, Wales and Northern Ireland (see above). In general, it was possible to harmonise the statistics for regional comparisons of age-standardised admission ratios. For some of the rarer lung diseases, the researchers aggregated small age- or gender- or year-specific counts for confidentiality reasons. In such cases, the missing counts were imputed, before the age-standardisation. This was done by applying the English age or gender or year distribution to the aggregated counts from the other nations.

Social deprivation

The Townsend deprivation index was used to estimate the impact of social deprivation on individual lung diseases. This index is a census-based method of measuring social deprivation. It uses variables such as unemployment (applying to either parent or guardian in instances of child lung disease), and whether a household owns a car, is overcrowded and is owner-occupied.

Limitations

The socio-economic analysis was conducted by applying the Townsend index to THIN data. So the same limitations as those detailed for incidence and prevalence data apply.

International comparison

The WHO World Detailed Mortality Database provided comparisons of lung disease mortality for 99 countries. The researchers compared deaths against United Nations population estimates for the years from 2000 to 2010.

Limitations

Data for many countries were available for all 10 years analysed. But data from some countries were not available for every year.

There are differences in data-recording techniques and health services. This makes it difficult to know the extent to which these data reflect actual rates, or differences in diagnostic conventions.

Lung disease in the UK
The big picture

What is lung disease?

Lung disease refers to a wide range of conditions that affect the lungs, the organs through which we breathe. There are a number of causes of lung disease. Smoking is the main cause for the two biggest killers, lung cancer and chronic obstructive pulmonary disease (COPD). Pneumonia, the third biggest cause of death from lung disease, is caused by infection. Other diseases may result from exposure to harmful substances, such as asbestos, which causes lung fibrosis and mesothelioma. Cystic fibrosis, on the other hand, is a genetic disorder that is inherited.

Most of the 15 major lung diseases included in this report are life threatening. Those that are less so can have a debilitating impact on your quality of life. Living with such a disease can mean that you can't leave your home, walk more than a few paces or dress yourself. Some diseases, like asthma, can usually be managed effectively with the right treatment.

Prevalence

Around one in five (12 million) people in the UK have received a diagnosis of lung disease.

Table 1 shows how many people living in the UK were diagnosed with some of the major lung diseases before 2013. Asthma is by far the most common, accounting for over 8 million diagnoses. COPD is the second most common.

Table 1: **Estimated numbers of people alive in the UK on 1 January 2013 with a diagnosis of lung disease at any time in the past**

	Asthma	Bronchiectasis	COPD	IPF	Lung cancer	Mesothelioma	Obstructive sleep apnoea	Sarcoidosis
Overall	8,028,741	211,598	1,201,685	32,479	85,796	5,419	201,411	107,824
By gender								
male	3,873,724	88,993	627,019	19,450	45,329	4,255	152,074	52,514
female	4,155,017	122,606	574,666	13,028	40,467	1,164	49,337	55,310

Incidence

Around 550,000 new diagnoses of lung disease are made each year, equivalent to 1,500 a day. This is 80% higher than the number of non-respiratory cancer diagnoses a year. As **Table 2** shows, asthma and COPD alone accounted for nearly 275,000 new diagnoses in 2012.

Table 2: **Estimated number of people first diagnosed in 2012**

	Asthma	Bronchiectasis	COPD	IPF*	Lung cancer	Mesothelioma	Obstructive sleep apnoea	Sarcoidosis
Overall	160,090	19,177	114,219	7,865	32,226	2,319	18,998	4,579
By gender								
male	75,378	8,322	61,448	4,968	17,168	1,892	13,810	2,175
female	84,712	10,855	52,771	2,897	15,058	427	5,187	2,404

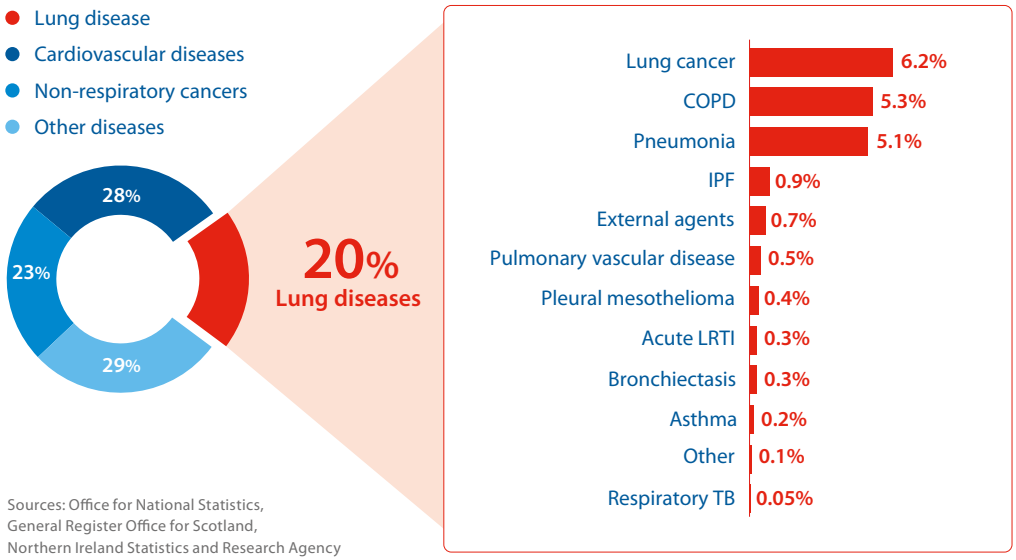
*IPF estimate higher than expected – see IPF section for further detail

Between 2008 and 2012 the incidence of some individual diseases went up. For others it went down or stabilised. We can infer the reasons for these trends more easily in some cases than in others. For example, the plateauing of mesothelioma incidence reflects the tail-off of asbestos use in the 1970s before the complete ban in 1999. But it is less obvious why, for instance, more people are being diagnosed with bronchiectasis. This could be due to a better understanding of the disease and more accurate diagnoses. Or it could because bronchiectasis is becoming more common, due to an ageing population or other reasons.

Mortality

Lung disease kills around 115,000 people a year. This is the equivalent of one in five of all deaths, and to one person dying from lung disease every five minutes. It is therefore one of the UK's three biggest killer disease areas, alongside cardiovascular disease and non-respiratory cancer. The three biggest causes of death from lung disease are, in order, lung cancer, COPD and pneumonia.

Figure 1: **Percentage of deaths by disease group (all ages over 28 days, UK 2012)**



Sources: Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

Age-standardised death rates for lung disease fell by 50% between 1970 and 2010. This is considerably lower than the 70% decline for ischaemic heart disease over the same period. **Table 3** shows that the number of people killed by cardiovascular disease from 2008 to 2012 fell by 26,000 (15%). But the number of deaths from lung disease did not alter much, accounting for 20% of all deaths throughout the period. Indeed, the number of people dying from lung disease has not changed much since 2004. The figure for that year was 117,456, as reported by the British Thoracic Society ten years ago.

Table 3: **UK deaths (number and percentage) by cause, all ages (over 28 days), 2008-2012**

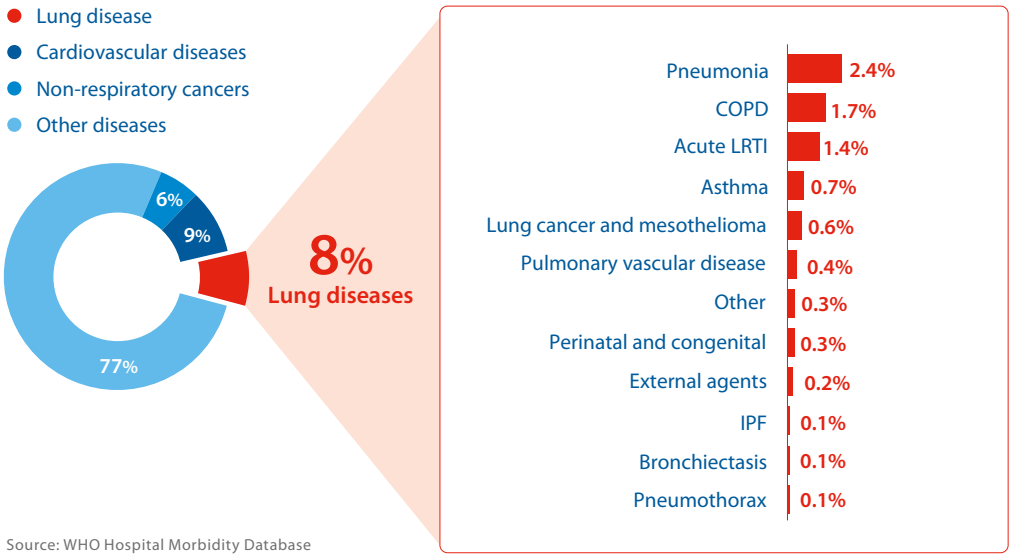
Data shown are numbers of deaths and % of all deaths	2008		2009		2010		2011		2012	
All causes, all ages	577,398		557,366		559,518		550,029		566,924	
Respiratory diseases	115,928	20%	111,775	20%	110,961	20%	110,921	20%	114,225	20%
Cardiovascular diseases	184,518	32%	177,282	32%	175,320	31%	156,745	28%	158,383	28%
Non-respiratory cancers	121,319	21%	120,678	22%	123,943	22%	125,521	23%	127,968	23%
Other causes	155,633	27%	147,631	26%	149,294	27%	156,842	29%	166,348	29%
Respiratory deaths	**115,928**		**111,775**		**110,961**		**110,921**		**114,225**	
Lung cancer	35,333	6.1%	35,071	6.3%	34,941	6.2%	35,238	6.4%	35,419	6.2%
COPD	28,344	4.9%	26,843	4.8%	27,164	4.9%	28,084	5.1%	29,776	5.3%
Pneumonia	32,282	5.6%	29,909	5.4%	28,405	5.1%	28,381	5.2%	28,952	5.1%
IPF	3,964	0.7%	3,977	0.7%	4,323	0.8%	4,992	0.9%	5,292	0.9%
Lung diseases caused by external agents	3,728	0.6%	3,466	0.6%	3,751	0.7%	3,756	0.7%	4,171	0.7%
Pleural mesothelioma	2,160	0.4%	2,293	0.4%	2,291	0.4%	2,312	0.4%	2,431	0.4%
Pulmonary embolism	3,335	0.6%	3,228	0.6%	3,245	0.6%	2,282	0.4%	2,275	0.4%
Acute LRTI	2,911	0.5%	2,879	0.5%	2,917	0.5%	1,516	0.3%	1,589	0.3%
Bronchiectasis	1,150	0.2%	1,214	0.2%	1,218	0.2%	1,332	0.2%	1,567	0.3%
Asthma	1,205	0.2%	1,134	0.2%	1,147	0.2%	1,168	0.2%	1,246	0.2%
Pulmonary vascular diseases (other than pulmonary embolism)	525	<0.1%	523	<0.1%	512	<0.1%	543	0.1%	594	0.1%
Respiratory tuberculosis	381	<0.1%	352	<0.1%	316	<0.1%	293	<0.1%	282	<0.1%
Sarcoidosis	137	<0.1%	148	<0.1%	149	<0.1%	159	<0.1%	170	<0.1%
Acute respiratory failure	160	<0.1%	148	<0.1%	126	<0.1%	149	<0.1%	127	<0.1%
Perinatal and congenital respiratory conditions	140	<0.1%	142	<0.1%	148	<0.1%	102	<0.1%	119	<0.1%
Cystic fibrosis	122	<0.1%	147	<0.1%	107	<0.1%	116	<0.1%	111	<0.1%
Influenza	51	<0.1%	301	<0.1%	201	<0.1%	498	<0.1%	104	<0.1%

Sources: Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

Impact on hospital services

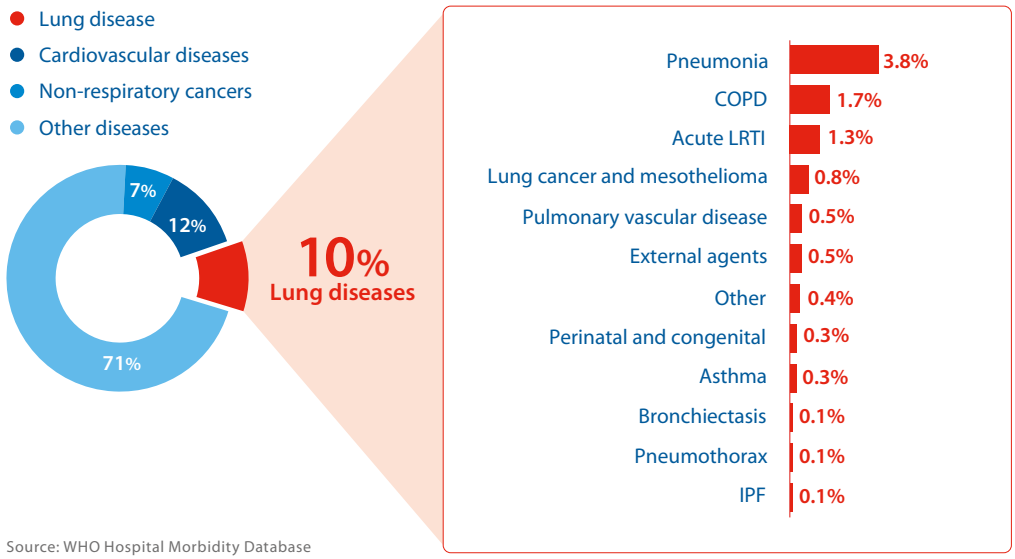
Lung disease places a huge burden on health services. It accounts for over 700,000 hospital admissions and over 6.1 million hospital bed days in the UK each year. This is equivalent to 8% of all admissions and 10% of all bed days. In this respect, it sits between heart disease and non-respiratory cancers. Heart disease accounts for slightly more – 9% of all admissions and 12% of all bed days – and non-respiratory cancers account for slightly less – 6% of all admissions and 7% of all bed days.

Figure 2:
Percentage of hospital admissions by disease group and respiratory condition, UK 2011



Source: WHO Hospital Morbidity Database

Figure 3:
Percentage of bed days by disease group and respiratory condition, UK 2011



Source: WHO Hospital Morbidity Database

Table 4: **Hospital admissions and bed days, UK 2011**

	Admissions		Bed days	
	Number	Share of all admissions	Number	Share of all hospital bed days
All causes	8,423,780		61,749,654	
Respiratory diseases	703,116	8%	6,167,509	10%
Cardiovascular diseases	769,774	9%	7,391,348	12%
Non-respiratory cancers	511,182	6%	4,161,822	7%
Other diseases	6,439,708	76%	44,028,975	71%
Respiratory diseases	**703,116**	**8.3%**	**6,167,509**	**10.0%**
Pneumonia	204,798	2.4%	2,346,324	3.8%
COPD	141,284	1.7%	1,044,629	1.7%
Acute LRTI	121,326	1.4%	792,583	1.3%
Asthma	59,014	0.7%	200,629	0.3%
Lung cancer	44,800	0.5%	465,323	0.8%
Pulmonary embolism	27,560	0.3%	254,058	0.4%
Perinatal and congenital respiratory conditions	25,359	0.3%	185,334	0.3%
Lung diseases caused by external agents	18,263	0.2%	314,374	0.5%
Influenza	9,804	0.1%	74,898	0.1%
Cystic fibrosis	9,541	0.1%	102,152	0.2%
Pneumothorax	9,211	0.1%	64,352	0.1%
IPF	8,826	0.1%	85,860	0.1%
Bronchiectasis	8,487	0.1%	88,198	0.1%
Pulmonary vascular diseases (other than pulmonary embolism)	3,791	<0.05%	30,756	<0.05%
Pleural mesothelioma	3,740	<0.05%	30,884	0.1%
Acute respiratory failure	3,345	<0.05%	33,874	0.1%
Respiratory tuberculosis	2,707	<0.05%	43,957	0.1%
Sarcoidosis	1,260	<0.05%	9,324	<0.05%

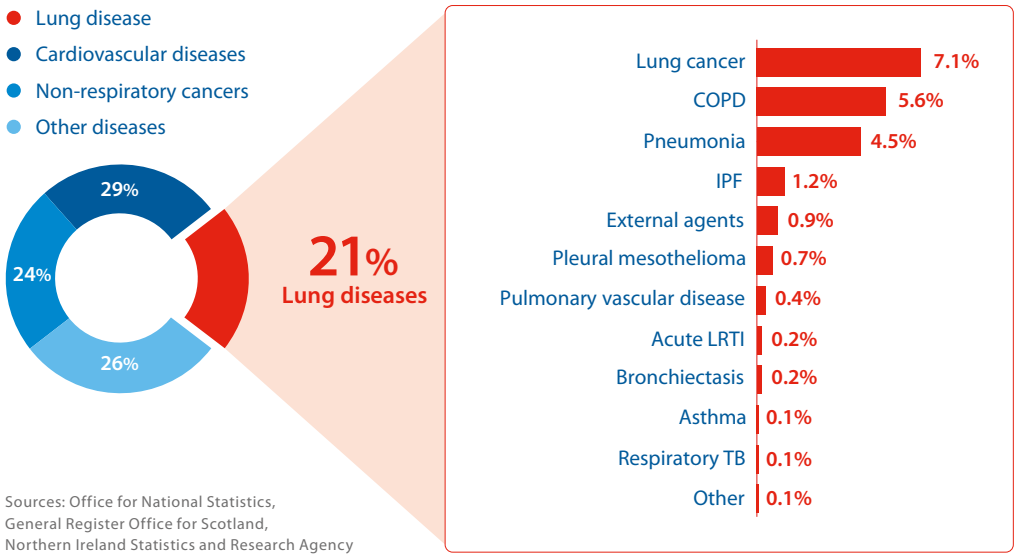
Source: WHO Hospital Morbidity Database

As **Table 4** shows, pneumonia accounts for significantly more admissions and bed days than any other lung disease. Acute lower respiratory tract infections other than pneumonia have the third highest number of admissions and bed days among all lung diseases.

Gender

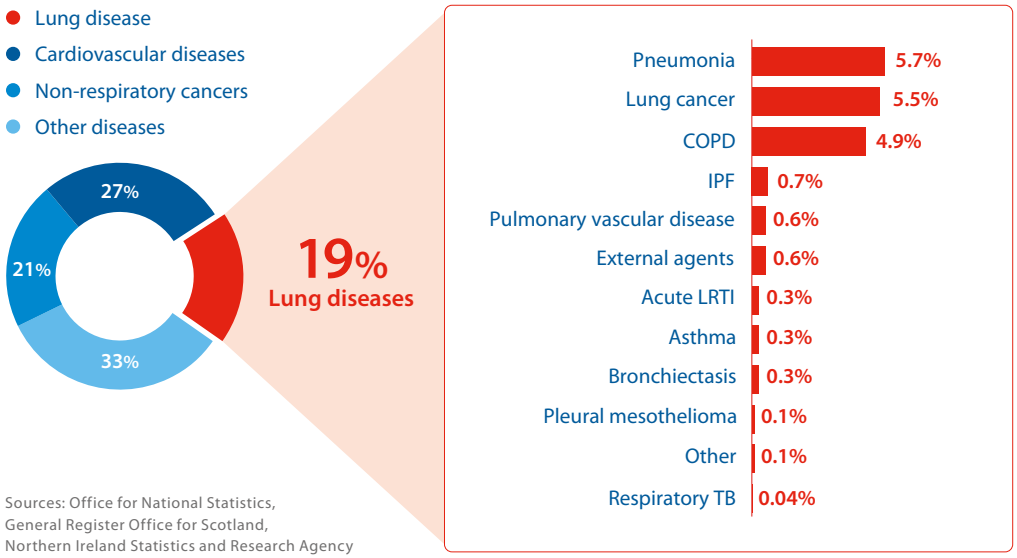
More women than men are living with a diagnosed lung disease, while marginally more men die from lung disease. As **Figures 4** and **5**, and **Table 5** show 21% of all male deaths and 19% of all female deaths are from lung disease.

Figure 4: **Percentage of deaths by major disease group and respiratory condition: males, all ages (over 28 days), UK 2012**



Sources: Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

Figure 5: **Percentage of deaths by major disease group and respiratory condition: females, all ages (over 28 days), UK 2012**



Sources: Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

Table 5: **UK deaths, all ages (over 28 days) by cause and gender, 2012**

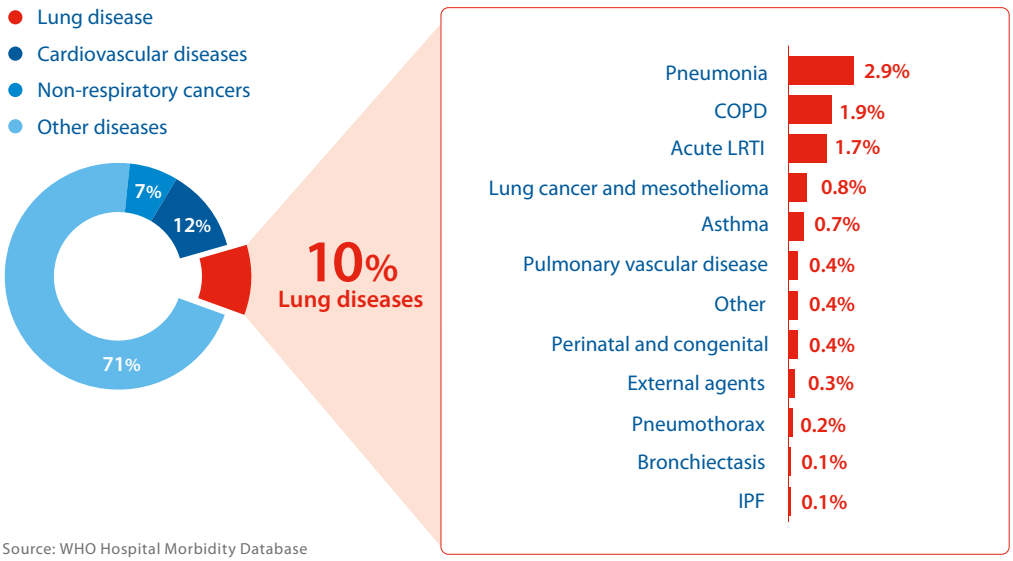
	All ages, males and females	% of all deaths	All ages, males	% of all male deaths	All ages, females	% of all female deaths
All causes, all ages	566,924		272,151		294,773	
Respiratory diseases	114,225	20%	57,621	21%	56,604	19%
Cardiovascular diseases	158,383	28%	78,001	29%	80,382	27%
Non-respiratory cancers	127,968	23%	65,693	24%	62,275	21%
Other diseases	166,348	29%	70,836	26%	95,512	32%
Respiratory deaths	**114,225**		**57,621**		**56,604**	
Lung cancer	35,419	6.2%	19,333	7.1%	16,086	5.5%
COPD	29,776	5.3%	15,245	5.6%	14,531	4.9%
Pneumonia	28,952	5.1%	12,239	4.5%	16,713	5.7%
IPF	5,292	0.9%	3,193	1.2%	2,099	0.7%
Lung diseases caused by external agents	4,171	0.7%	2,393	0.9%	1,778	0.6%
Pleural mesothelioma	2,431	0.4%	2,035	0.7%	396	0.1%
Pulmonary embolism	2,275	0.4%	835	0.3%	1,440	0.5%
Acute LRTI	1,589	0.3%	619	0.2%	970	0.3%
Bronchiectasis	1,567	0.3%	661	0.2%	906	0.3%
Asthma	1,246	0.2%	358	0.1%	888	0.3%
Pulmonary hypertension and other pulmonary vascular diseases (excluding pulmonary embolism)	594	0.1%	214	0.1%	380	0.1%
Respiratory tuberculosis	282	<0.05%	177	0.1%	105	<0.05%
Sarcoidosis	170	<0.05%	83	<0.05%	87	<0.05%
Acute respiratory failure	127	<0.05%	62	<0.05%	65	<0.05%
Perinatal and congenital respiratory conditions	119	<0.05%	74	<0.05%	45	<0.05%
Cystic fibrosis	111	<0.05%	54	<0.05%	57	<0.05%
Influenza	104	<0.05%	46	<0.05%	58	<0.05%

Sources: Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

Table 5 also shows that there are significant gender splits in the mortality figures for certain diseases. Pneumonia kills more women than men because it is most common in older age, and women live longer than men. The difference between the number of male and female deaths from lung cancer reflects historically higher rates of smoking among men. It could also reflect men's greater exposure to harmful dust and fumes in the workplace. Similarly, the figures for mesothelioma point to men's greater exposure in the past to asbestos in heavy industry and the armed forces.

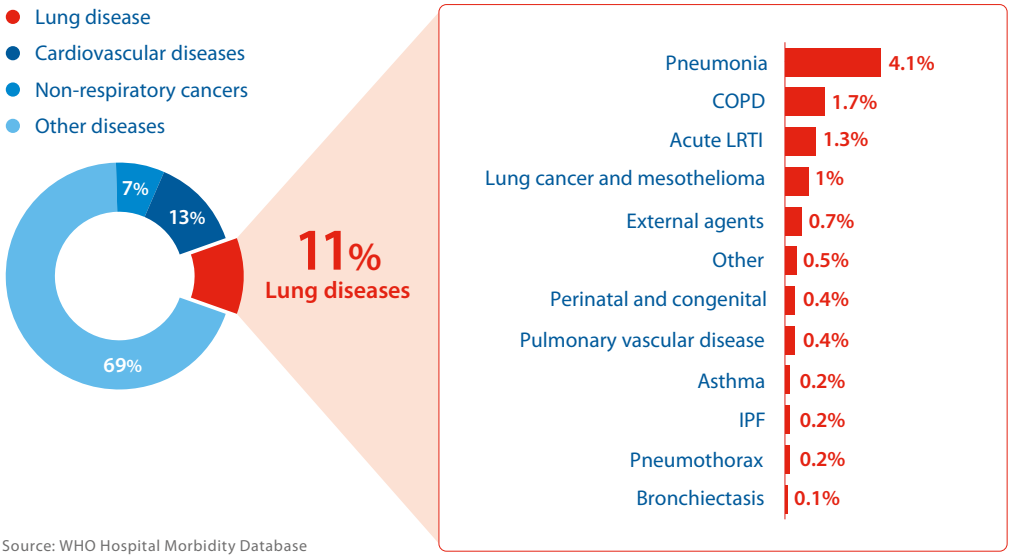
Figures 6 to **9** show that 10% of male and 7% of female hospital admissions are due to lung disease. There is slightly less difference in bed days. Lung disease accounts for 11% of bed days for males and 9% of bed days for females.

Figure 6: **Percentage of admissions by major disease group and respiratory condition: males, all ages, UK, 2011**



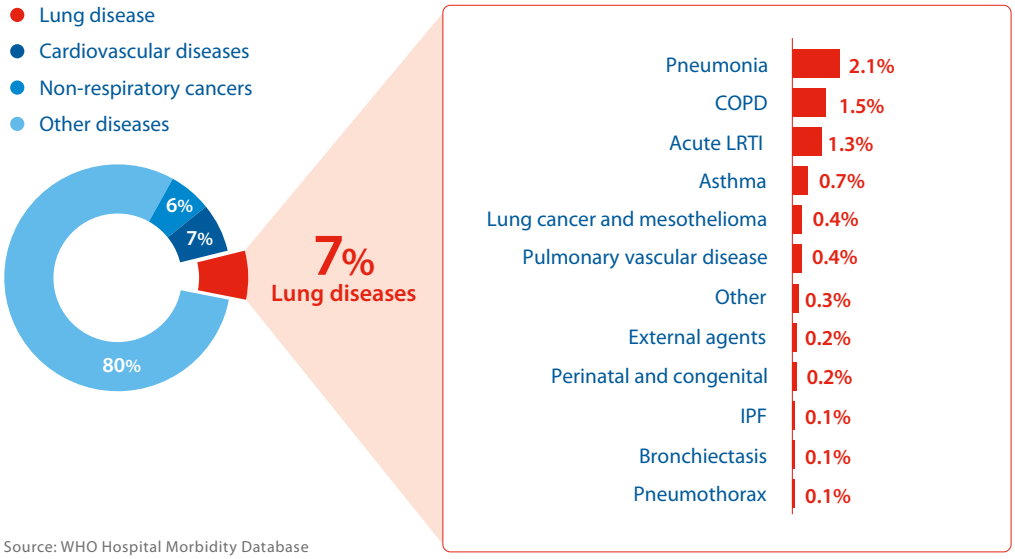
Source: WHO Hospital Morbidity Database

Figure 7: **Percentage of bed days by major disease group and respiratory condition: males, all ages, UK, 2011**



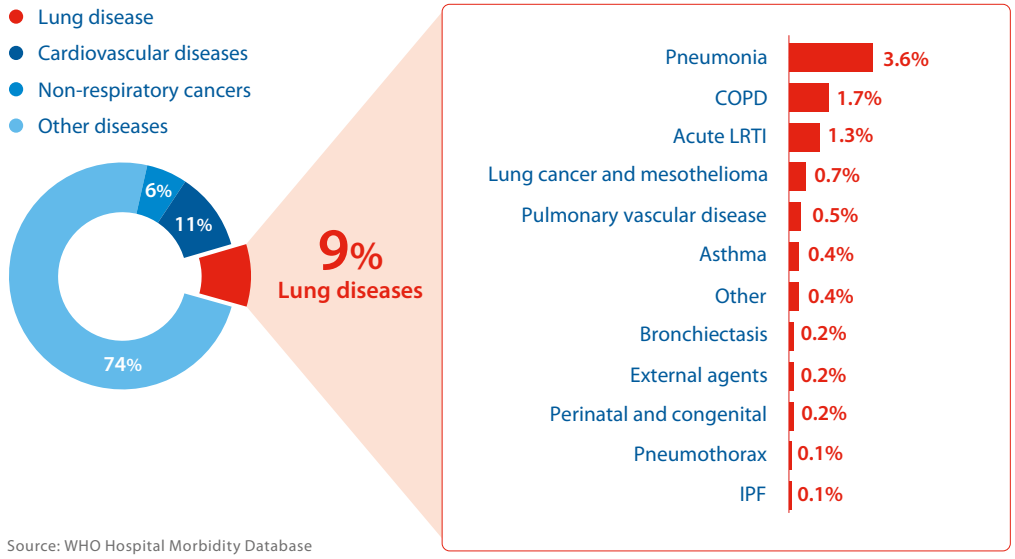
Source: WHO Hospital Morbidity Database

Figure 8: **Percentage of admissions by major disease group and respiratory condition: females, all ages, UK, 2011**



Source: WHO Hospital Morbidity Database

Figure 9: **Percentage of bed days by major disease group and respiratory condition: females, all ages, UK, 2011**



Source: WHO Hospital Morbidity Database

Age

Lung disease is less common in children than in adults. As **Table 6** shows the majority of deaths from lung disease (over 100,000) are in people aged 65 and above.

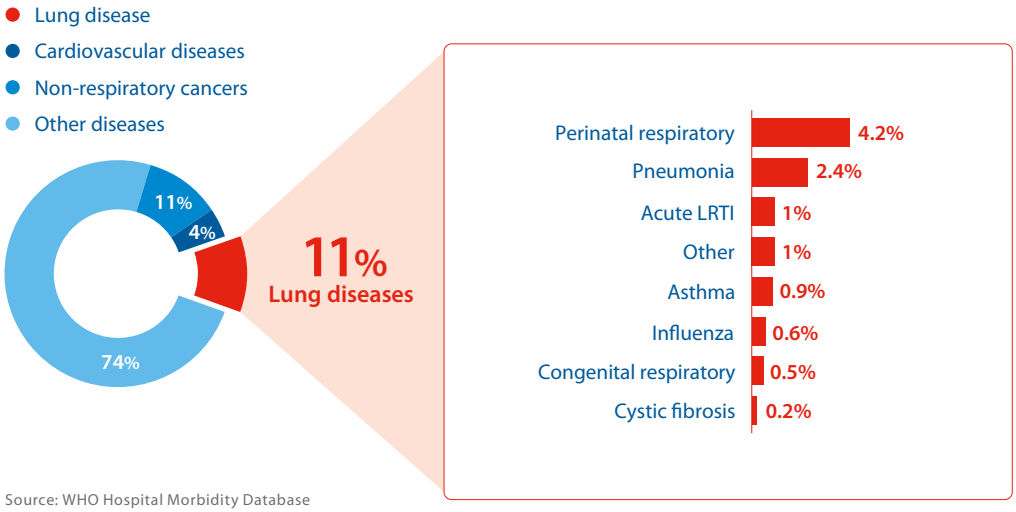
Table 6: **UK deaths (aged over 28 days) by cause and age group, 2012**

	All ages over 28 days	Share of all deaths	Ages 0-14	Share of all 0-14 deaths	Ages 15-64	Share of all 15-64 deaths	Ages 65+	Share of all 65+ deaths
All causes	566,924		2,435		87,979		476,510	
Respiratory diseases	114,225	20%	262	11%	13,739	16%	100,224	21%
Cardiovascular diseases	158,383	28%	102	4%	17,542	20%	140,739	30%
Non-respiratory cancers	127,968	23%	278	11%	27,628	31%	100,062	21%
Other diseases	166,348	29%	1,793	74%	29,070	33%	135,485	28%
Respiratory deaths	**114,225**	**20.1%**	**262**	**10.8%**	**13,739**	**15.6%**	**100,224**	**21.0%**
Lung cancer	35,419	6.2%	0	0.0%	7,366	8.4%	28,053	5.9%
COPD	29,776	5.3%	1	<0.05%	2,719	3.1%	27,056	5.7%
Pneumonia	28,952	5.1%	58	2.4%	1,374	1.6%	27,520	5.8%
IPF	5,292	0.9%	3	0.1%	475	0.5%	4,814	1.0%
Lung diseases caused by external agents	4,171	0.7%	5	0.2%	320	0.4%	3,846	0.8%
Pleural mesothelioma	2,431	0.4%	0	0.0%	340	0.4%	2,091	0.4%
Pulmonary embolism	2,275	0.4%	1	0.0%	358	0.4%	1,916	0.4%
Acute LRTI	1,589	0.3%	25	1.0%	59	0.1%	1,505	0.3%
Bronchiectasis	1,567	0.3%	0	0.0%	123	0.1%	1,444	0.3%
Asthma	1,246	0.2%	21	0.9%	204	0.2%	1,021	0.2%
Pulmonary hypertension and other pulmonary vascular diseases (excluding pulmonary embolism)	594	0.1%	13	0.5%	114	0.1%	467	0.1%
Respiratory tuberculosis	282	<0.05%	0	0.0%	65	0.1%	217	<0.05%
Sarcoidosis	170	<0.05%	0	0.0%	76	0.1%	94	<0.05%
Acute respiratory failure	127	<0.05%	1	<0.05%	22	<0.05%	104	<0.05%
Perinatal and congenital respiratory conditions	119	<0.05%	115	4.7%	4	<0.05%	0	0.0%
Cystic fibrosis	111	<0.05%	4	0.2%	105	0.1%	2	<0.05%
Influenza	104	<0.05%	15	0.6%	15	<0.05%	74	<0.05%

Sources: Office for National Statistics, General Register Office for Scotland, Northern Ireland Statistics and Research Agency

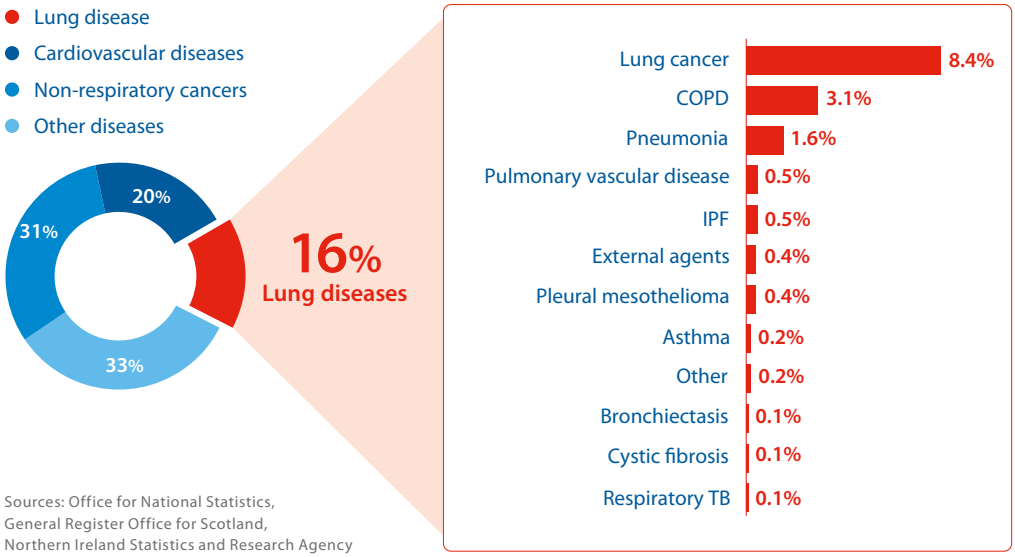
However, lung disease accounts for 11% of deaths in children under 15, killing around five children a week. **Figures 10** to **12** show how the proportion of deaths from lung disease, in relation to heart disease and non-respiratory cancers, changes across age groups. While non-respiratory cancers also account for 11% of deaths in children under 15, heart disease accounts for 4%.

Figure 10: Percentage of admissions by major disease group and respiratory condition ages 0-14 years, UK, 2011



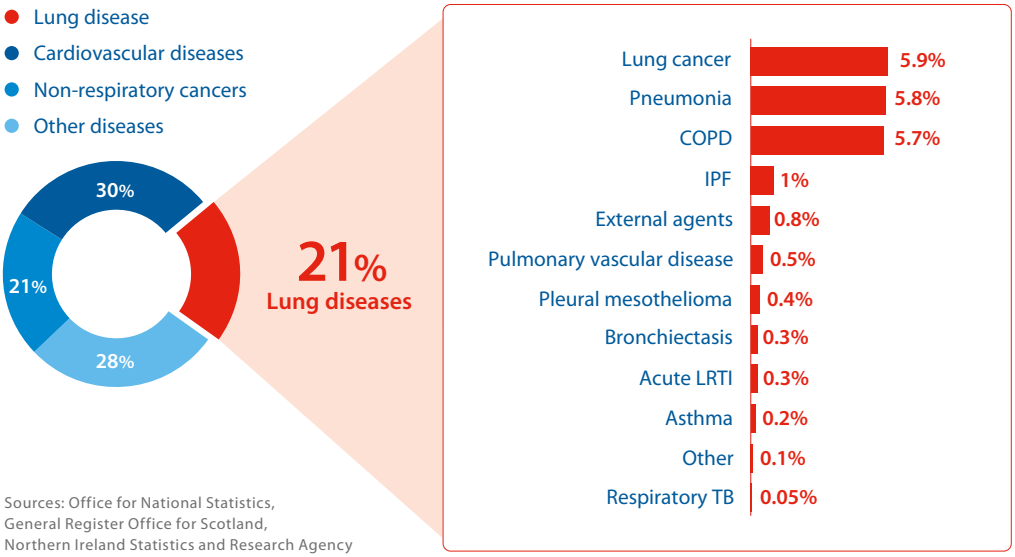
Source: WHO Hospital Morbidity Database

Figure 11: Percentage of deaths by major disease group and respiratory condition ages 15-64 years, UK, 2012



Sources: Office for National Statistics,
General Register Office for Scotland,
Northern Ireland Statistics and Research Agency

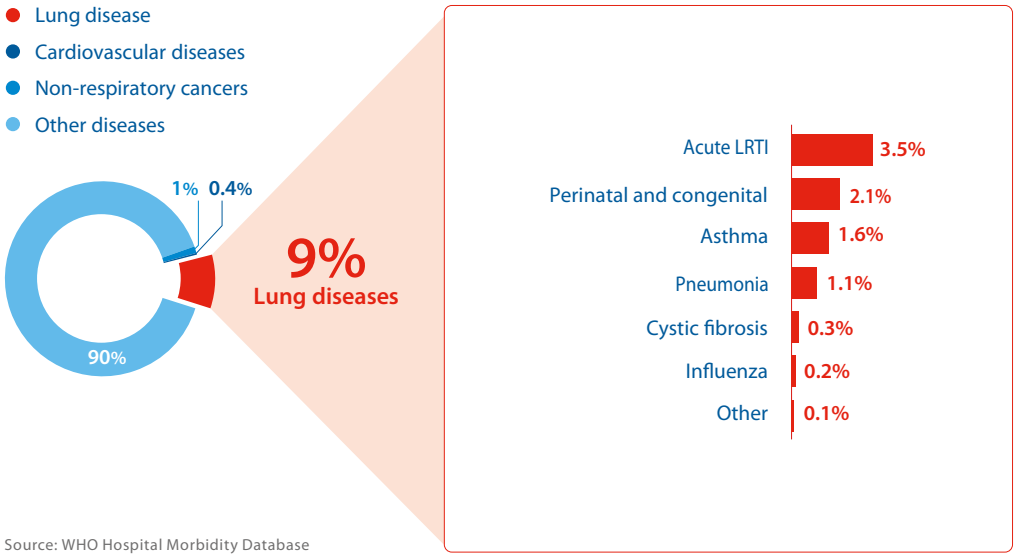
Figure 12: Percentage of deaths by major disease group and respiratory condition ages 65+ years, UK, 2012



Sources: Office for National Statistics,
General Register Office for Scotland,
Northern Ireland Statistics and Research Agency

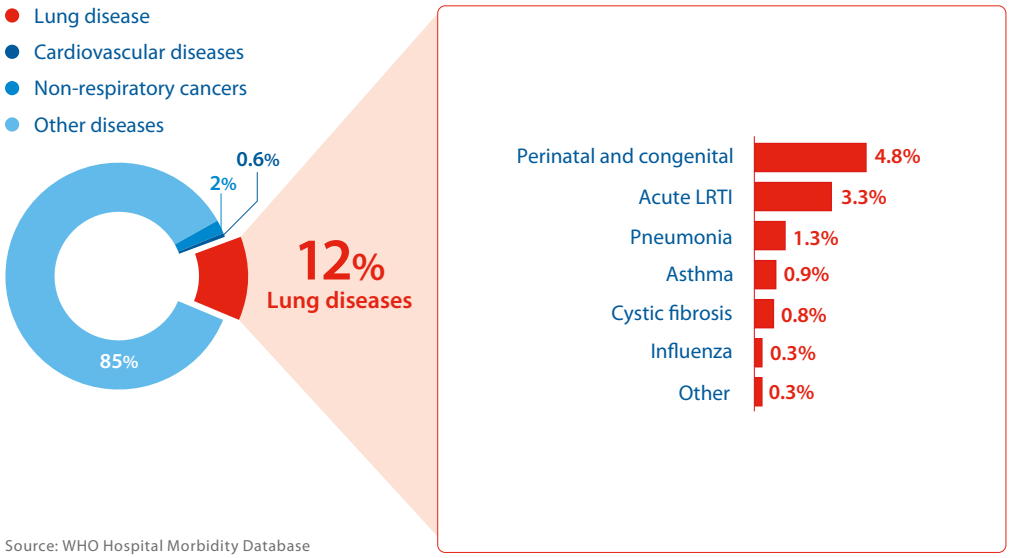
Lung disease also accounts for 9% of hospital admissions and bed days for children. This is nine times the proportion accounted for by non-respiratory cancers, and 21 times that accounted for by heart disease.

Figure 13: **Percentage of admissions by major disease group and respiratory condition ages 0-14 years, UK, 2011**



Source: WHO Hospital Morbidity Database

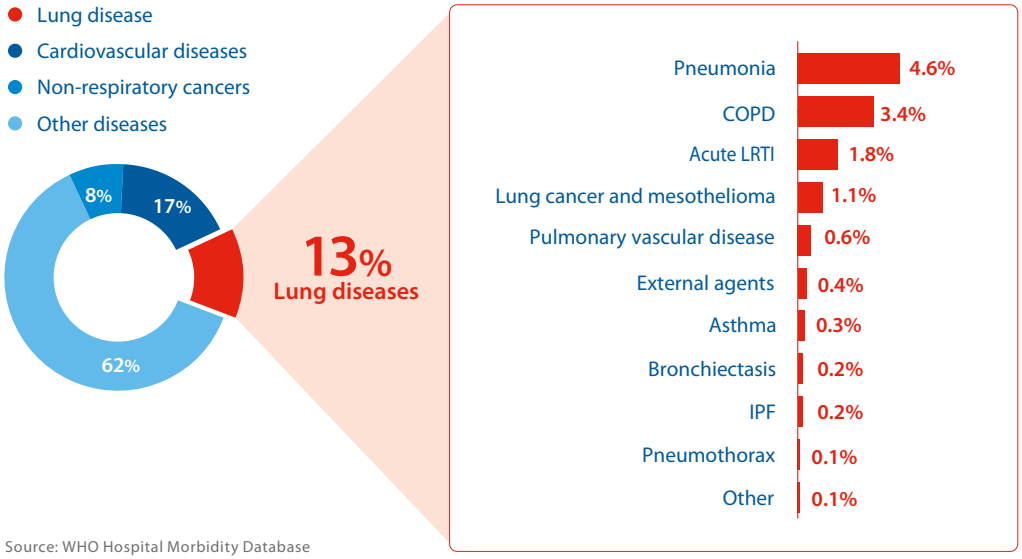
Figure 14: **Percentage of bed days by major disease group and respiratory condition ages 0-14 years, UK, 2011**



Source: WHO Hospital Morbidity Database

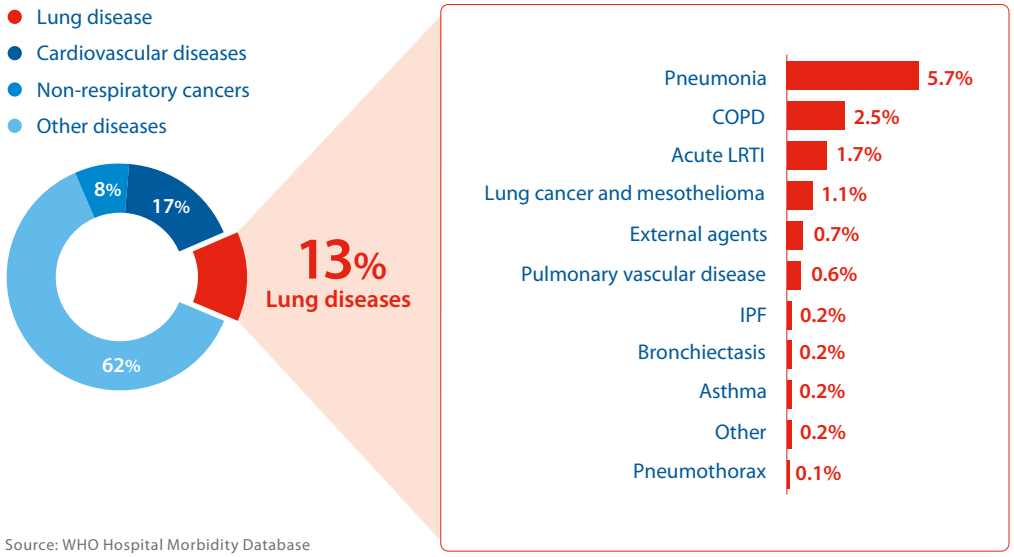
The relative proportions of admissions and bed days for these disease groups change significantly in older age groups, as illustrated in **Figures 15-18**.

Figure 15: **Percentage of admissions by major disease group and respiratory condition ages 15-64 years, UK, 2011**



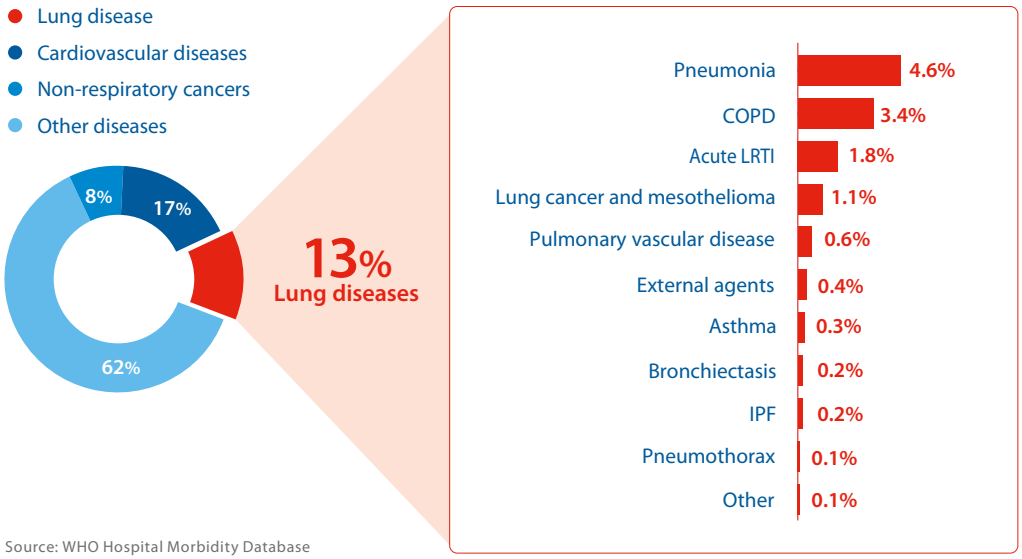
Source: WHO Hospital Morbidity Database

Figure 16: **Percentage of bed days by major disease group and respiratory condition ages 15-64 years, UK, 2011**



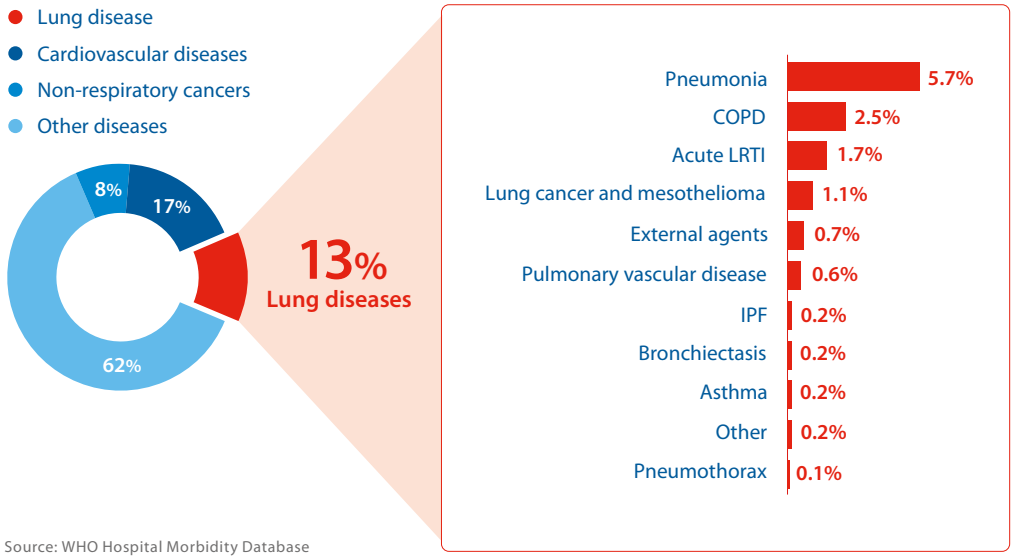
Source: WHO Hospital Morbidity Database

Figure 17: **Percentage of admissions by major disease group and respiratory condition ages 65+ years, UK, 2012**



Source: WHO Hospital Morbidity Database

Figure 18: **Percentage of bed days by major disease group and respiratory condition ages 65+ years, UK, 2011**



Source: WHO Hospital Morbidity Database

Regional variation

Lung disease mortality is highest in the north-west, north-east and urban Scotland and parts of south Wales. This is heavily influenced by the number of deaths from COPD and lung cancer, over 80% of which are smoking-related.

Urban areas in the north of England have higher hospital admission rates (see **Figure 19**). Otherwise, there is no clear pattern in regional variations in hospital admissions. The regional impact of lung disease on health services is better understood on a condition by condition basis, and is covered further in the individual disease sections of this report.

Figure 19:
Adjusted all-cause respiratory hospital admissions in Great Britain, 2010

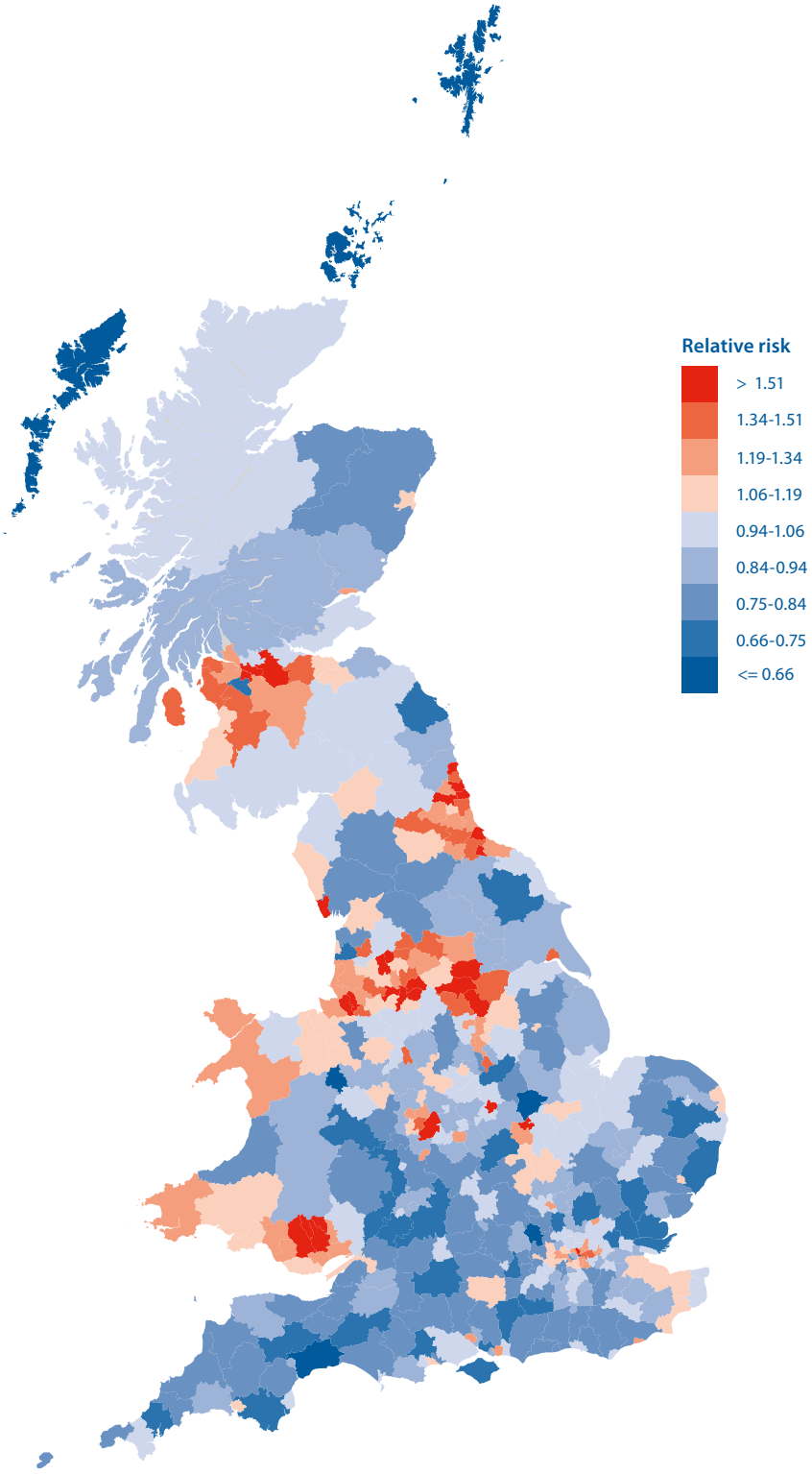
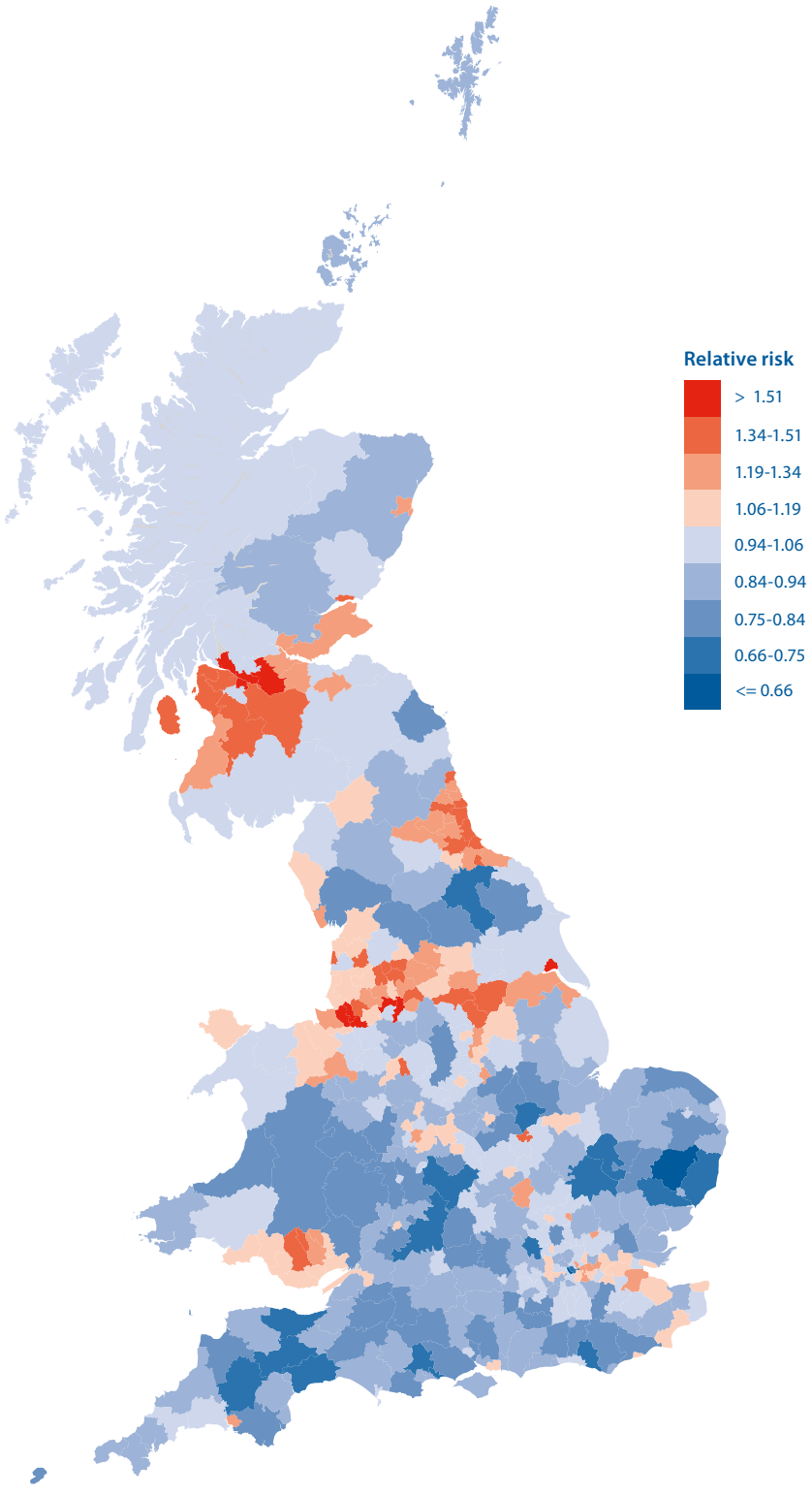


Figure 20:
Adjusted all-cause respiratory mortality in Great Britain, 2008-2012



Socio-economic analysis

Although the links between lung disease and levels of social deprivation vary depending on the condition, there are clear inequalities in a range of lung conditions.

For instance, COPD and lung cancer are both considerably more common in more socially deprived communities. This is expected due to their association with smoking. Higher smoking rates in more deprived sections of society continue to this day, something that needs to be addressed in order to tackle lung health inequalities.

Outdoor air pollution, which is generally higher in deprived urban areas, may also be a factor in these inequalities. Diesel fumes in particular are known to worsen symptoms in a range of conditions. Diesel is also classified as a cause of lung cancer by the WHO and there is emerging evidence that it may cause asthma. However, more research is required to understand the correlation of asthma with social deprivation.

In some cases, the link between the prevalence of a disease and socio-economic status is not as we expected. For example, mesothelioma is associated with traditionally working-class professions in heavy industry. The condition is common in many deprived areas. Yet, its prevalence appears to increase with affluence. This inverse relationship may be because the prognosis is better for more affluent groups. This could be due to earlier diagnosis, better medical care, or fewer comorbid conditions. These are areas in need of research.

Bronchiectasis and sarcoidosis are also more prevalent in the least deprived communities. With regards to the bronchiectasis data in particular, this may be because smoking prevalence is higher among the most deprived, potentially making them more likely to be diagnosed as solely having COPD (which is strongly associated with smoking). Also, more affluent people may be more likely to demand further investigations with a CT scan to ensure an accurate diagnosis. That bronchiectasis prevalence is higher in less deprived groups, yet incidence is the same, suggests the greater deprivation seems to shorten the time you live after diagnosis. There could be a higher death rate among more deprived groups due to more comorbid conditions. These are all areas in need of further investigation.

Some conditions, such as IPF, showed no association between incidence and socio-economic status. This contrasts with other fibrotic lung diseases that are linked to workplace exposure to harmful substances like silica or asbestos. (The link between workplace dusts and chemicals is likely to increase lung health inequalities.) More research is needed to understand these more counterintuitive results of our socio-economic analyses.

International comparison

The UK has the fourth highest age-standardised lung disease mortality rates in Europe, after Denmark, Hungary and Romania. This was calculated by combining WHO data on age-standardised mortality rates for five conditions that are common causes of respiratory death worldwide. These were pneumonia, acute lower respiratory tract infections, lung cancer, COPD and respiratory TB.

We also found that the UK ranks 14th out of the 99 countries worldwide for which mortality data for these conditions are available. However, it is difficult to know the extent to which these data reflect actual rates or differences in diagnosis rates. This is due to differences in data recording techniques and health services in different countries.

Asthma

What is asthma?

Asthma is a common, long-term disease that requires ongoing management. If you have asthma, you have very sensitive airways – the tubes that carry air in and out of your lungs. Certain triggers can cause your airways to become inflamed and tighten when you breathe. Triggers can include stress, exercise, cold air, and breathing in particular substances such as smoke, pollution or pollen.

We do not know for certain what causes asthma, although we do know that many things can make it worse. Asthma often runs in families and people who have allergies – especially those under the age of 16 – are at a higher risk. Some people can develop asthma by repeatedly breathing in certain substances, especially while they're at work. Many chemicals and types of dust and moulds can cause asthma.

Asthma is usually treated with medication taken through an inhaler.

Asthma in the UK

Prevalence

We found that 8 million people – over 12% of the population – have been diagnosed with asthma. This means more people have had an asthma diagnosis than have been diagnosed with all other lung diseases combined.

This does not mean that there are 8 million people living with the condition, however. Many children diagnosed with asthma grow out of it. Asthma UK states that around 5.4 million people receive treatment for the disease. Research has also suggested asthma maybe considerably over-diagnosed.

Further research is needed to understand if this is a more accurate indication of the number of people living with asthma in the UK. Or whether this is an underestimate due to the number of people who no longer take treatment for asthma in adulthood, despite still having symptoms.

Our data also confirm that the number of people who have had a diagnosis of asthma is plateauing. There has only been a small increase of under 3% in recent years. However, asthma is still the most common lung condition by a considerable margin.

Incidence

Around 160,000 people a year receive an asthma diagnosis. This is more than are diagnosed with any other lung condition. However, incidence rates went down by around 10% between 2008 and 2012.

We need further research to understand why. Possible reasons include:

- Asthma is becoming less common.
- Conditions like COPD are becoming less likely to be misdiagnosed as asthma.
- Better diagnosis has reduced the backlog of cases that failed to be diagnosed in the past. Consequently, only new cases are being diagnosed.

Mortality

Around 1,200 people a year are recorded as dying from asthma. Although low compared with most other lung diseases, this figure is still too high. Given the manageability of asthma, mortality should be closer to zero. The Royal College of Physicians' report *Why asthma still kills* (RCP 2015) details how managing the disease more effectively could dramatically reduce mortality.

Impact on hospital services

Asthma accounts for 60,000 hospital admissions and 200,000 bed days a year. Compared with conditions such as pneumonia and COPD, these figures are low. But like mortality rates, they are too high for such a manageable condition. It is also worth noting that many people with asthma attend accident and emergency units without needing admission, but still adding to the burden on health services.

Gender

Death rates among women are 50% higher than for men of the same age. This is concerning given that incidence is only around 10% higher and lifetime prevalence only 5% higher in women.

Without further research, we can only speculate why there is such a difference. A likely factor is that severe asthma, which is more likely to be fatal, is more common in women.

The difference may be partly related to a diagnostic overlap between asthma and COPD. COPD has a much higher mortality rate than asthma in all age groups. A small proportion of COPD deaths being miscertified as asthma would result in a large proportionate change in asthma mortality.

The reasons for the higher incidence and prevalence in women are unknown. Hormonal differences are thought to play a part. Research in children aged between five and 12 also suggests that girls are less likely to grow out of asthma.

Age

In contrast to other lung diseases, the incidence of asthma is far higher in children than in adults. However, the majority of asthma deaths occur in over 65s.

Regional variation

Regional incidence rates are generally higher in Scotland, Wales, Northern Ireland and (to a slightly lesser extent) north-west England. However, recorded mortality is much higher in the West Midlands and south-east England than the rest of the UK. It is 35% above average in the West Midlands and 15% above average in south-east England.

Ethnicity may be a factor in this regional variation: the West Midlands and south-east England have high populations of people of Indian and Pakistani heritage, in whom asthma is more common.

However, more research is needed to confirm and explain this mismatch between regions of higher incidence and higher mortality. We also need to investigate whether higher regional incidence rates are linked to the correlation of incidence with social deprivation.

Socio-economic analysis

In 2012 incidence rates were 36% higher in the most deprived communities than in the least deprived. Prevalence is around 11% higher. These trends are broadly consistent over time. Higher levels of damp housing and fungal spores, pollution and second-hand smoke among more deprived groups could be contributing factors. But further research is needed to fully understand this link.

Bronchiectasis (non-cystic fibrosis)

What is bronchiectasis?

Bronchiectasis can occur if your airways (bronchi) become damaged, causing them to become wider than normal. When this happens, they cannot clear the mucus that keeps them moist, and trap the dust and germs you breathe in. Mucus builds up and the airways can become infected by bacteria. If bacteria survive, the airways become inflamed and further damaged. Once the damage has occurred, it is permanent.

The known causes of damage include severe lung infection, lack of immunity to infection and severe allergic response to moulds. Bronchiectasis is not caused by smoking, but smoking can worsen the symptoms.

Bronchiectasis is sometimes linked with COPD, as they are both long-term obstructive lung diseases and can co-exist. However, they are two separate diseases.

Treatment helps prevent further damage and infections, and reduces symptoms. Very occasionally, the damaged areas can be removed with surgery.

Cystic fibrosis is a cause of bronchiectasis, but is covered in a separate section. The figures in this section all relate to non-cystic fibrosis bronchiectasis.

Bronchiectasis in the UK

Prevalence

Around 210,000 people in the UK were living with bronchiectasis in 2012. This is at least four times higher than the estimate commonly used by the NHS of around 50,000. From 2008 to 2012 prevalence increased by 20%, with the number of people recorded to be living with bronchiectasis going up by 40,000.

Other research published this year (Quint et al) suggests bronchiectasis prevalence could be in excess of 300,000. More research is required to confirm the number of people living with the condition, and to determine whether bronchiectasis is becoming more common, or being diagnosed more accurately.

The increase in prevalence could reflect the reclassification of diseases, and a better understanding of the importance of the condition.

Incidence

Each year, some 20,000 people are diagnosed with bronchiectasis. From 2008 to 2012 the number of diagnoses per 100,000 population rose by over 25%.

Again, more research is required to determine whether this is due to more accurate diagnosis or bronchiectasis becoming more common.

Mortality

From 2008 to 2012 recorded deaths from bronchiectasis went up by 30%, from 1,150 to 1,500. This death rate is considerably higher than the estimate of 1,000 widely used by the NHS (2015).

This rise in mortality could be related to the similar increase in prevalence.

Impact on hospital services

Bronchiectasis accounts for around 8,500 hospital admissions and around 90,000 hospital bed days a year. This is relatively low compared with the number of people diagnosed with the condition.

Gender

Around 35% more women than men are diagnosed with bronchiectasis each year. This reinforces that the disease is more common in women, as previous research has indicated. Possible reasons for this include:

- Women are more likely to live into their 70s and 80s when most cases of bronchiectasis are diagnosed.
- Men are more likely than women to have smoked heavily. This increases the likelihood that they will be diagnosed with COPD. Meanwhile a bronchiectasis diagnosis may be considered more often for women with the same symptoms.

However, in those aged under 75, 20% more women than men die from bronchiectasis each year.

Age

Around 60% of bronchiectasis diagnoses are made in people aged over 70. Being diagnosed with the condition is more likely as you get older, between the ages of 30 and 70.

Regional variation

In 2012, prevalence in the West Midlands was twice as much per 100,000 than on the south-east coast, where it is lowest. While incidence rates were also high in the West Midlands, they were highest in Northern Ireland. In both, they were twice as high as in Wales, Yorkshire and Humber, and the south west, the areas of lowest incidence.

Mortality rates from 2008 to 2012 were highest in Northern Ireland. It was also relatively high in the West Midlands, the north-west and north-east.

In the same period emergency hospital admissions for bronchiectasis were much higher than expected in Northern Ireland, the West Midlands, East Midlands, Yorkshire and Humber, the north-west and north-east.

Further research is needed to investigate the reasons for these complex patterns of variation. Possibly, bronchiectasis is more often diagnosed, treated and recorded as a cause of death in regions with longstanding specialist clinics or experts in this condition.

Socio-economic analysis

In 2012 bronchiectasis was over 20% more prevalent in the least deprived communities than in the most deprived.

This could be related to:

- **diagnosis.** As smoking prevalence is higher among the most deprived, these groups may be more likely to be diagnosed as having only COPD, which – unlike bronchiectasis – is strongly associated with smoking. As a result, some cases of bronchiectasis may be missed or misdiagnosed as COPD. Also, more affluent people may be more likely to demand further investigations (a CT scan, for example) to ensure an accurate diagnosis.
- **life expectancy after diagnosis.** Greater deprivation is not linked to an increased chance of being diagnosed with bronchiectasis, but seems to shorten the time you live after diagnosis. There could be a higher death rate among more deprived groups due to more comorbid conditions. Less deprived groups may also self-manage better and have greater access to specialist services like physiotherapy, which can impact on survival.

However, more research is urgently required to fully understand the reasons behind this.

Chronic obstructive pulmonary disease (COPD)

What is chronic obstructive pulmonary disease?

Chronic obstructive pulmonary disease (COPD) is the name used to describe a number of conditions including emphysema and chronic bronchitis. Emphysema affects the air sacs (alveoli) in your lungs, and chronic bronchitis affects your airways (bronchi). If you have COPD, you might have just one of these conditions, or you might have more than one. Most COPD patients have varying degrees of both emphysema and chronic bronchitis.

With COPD, your airways become inflamed and the air sacs in your lungs are damaged. This causes your airways to become narrower, which makes it harder to breathe in and out. These breathing difficulties can affect many aspects of your daily life.

Smoking is the main cause of COPD in at least 80% of cases. It can also be caused by long-term exposure to fumes and dust from the environment or your place of work. You can also inherit COPD through a genetic condition called alpha-1 antitrypsin deficiency, although this is very rare.

There is no cure for COPD, but it can be managed. There are many treatments available and self-management can improve your symptoms and reduce flare-ups.

COPD in the UK

Prevalence

An estimated 1.2 million people are living with diagnosed COPD – considerably more than the 835,000 estimated by the Department of Health in 2011. In terms of diagnosed cases, this makes COPD the second most common lung disease in the UK, after asthma.

Around 2% of the whole population – 4.5% of all people aged over 40 – live with diagnosed COPD.

Our research also suggests that prevalence is growing. The number of people who have ever had a diagnosis of COPD has increased by 27% in the last decade, from under 1,600 to nearly 2,000 per 100,000. This could mean that more undiagnosed cases are being found, or that the disease is becoming more common. Changes in record-keeping could also be a factor. However, prevalence increased by 9% between 2008 and 2012, while record-keeping practices remained the same.

Earlier research has indicated that up to two-thirds of people with COPD remain undiagnosed. New research is required to see if this is still valid, and to ascertain the current prevalence of the disease.

Incidence

115,000 people are diagnosed with COPD each year – equivalent to a new diagnosis every five minutes.

In the five years up to 2008, incidence rates went down from 212 to 185 per 100,000. This could be due to changes in record-keeping, or could reflect a genuine fall in the number of people developing the condition. The data contrast with the rise in prevalence over the same period. Since 2008 incidence has been stable, with just under 115,000 new diagnoses recorded in 2012.

Mortality

Nearly 30,000 people die from COPD each year, making it the second biggest cause of death from lung disease. The disease is responsible for more deaths than any non-respiratory cancer and is the UK's fifth biggest killer.

Like the number of people living with COPD, the number dying from it is also growing. In 2012 mortality was 5% higher than in 2008, and 10% higher than in 2004.

Impact on hospital services

COPD accounts for over 140,000 hospital admissions and over a million bed days each year across the UK. This is 1.7% of all hospital admissions and bed days. Comparisons between regional and WHO data suggest around 97% of admissions are for emergency care. This huge burden on emergency services could be reduced by better diagnosis and self-management support for patients.

Gender

Men are 15% more likely to be diagnosed with COPD and there are 10% more men in the diagnosed population. More men also die from COPD. The differences are probably largely due to historically higher rates of smoking among men. Of the 29,776 people who died from the disease in 2012, 15,245 were men and 14,531 were women. This represents 5.6% of the total mortality for UK males, and 4.9% of the total mortality for UK females.

Age

COPD is rare under the age of 40 and becomes increasingly common with age. Around 1% of 41-50 year olds have diagnosed COPD. This rises to 2% of 51-60 year olds, 6% of 61-70 year olds, and 9% of those aged 71 or above.

Regional variation

COPD prevalence, incidence and mortality rates are highest in the north of England and Scotland. This correlates with historically higher smoking rates in these areas.

London has notably more hospital admissions for COPD than other regions with similar prevalence, such as the West Midlands. More research is required to find out why. Differences in service provision and pollution levels may play a part.

Socio-economic analysis

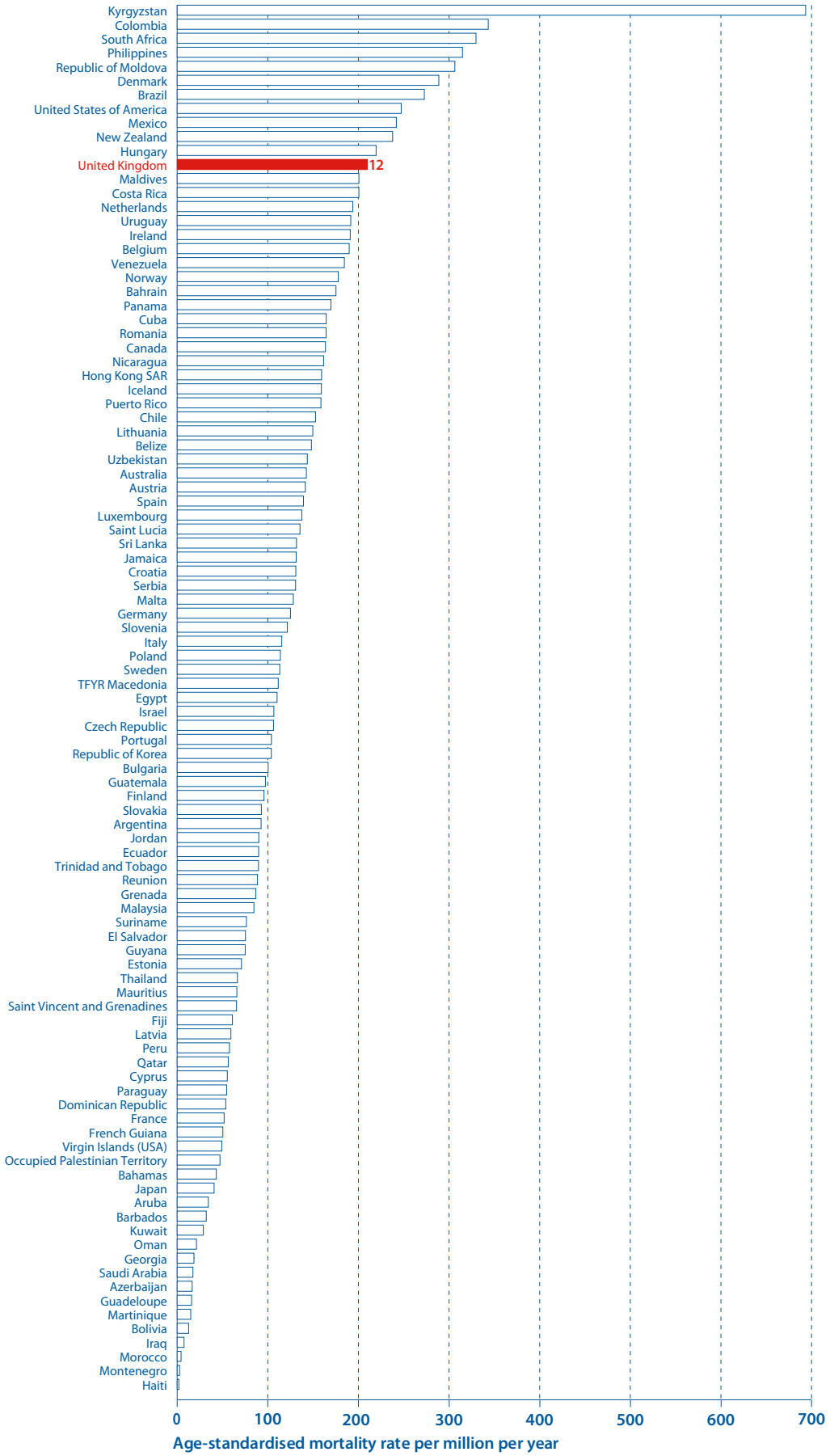
Prevalence is around 2.5 times greater, and incidence 2.2 times higher, in the most deprived quintile than in the least deprived. This in large part reflects higher rates of smoking among deprived groups. However, that socio-economic variation for COPD is more striking than for lung cancer suggests other factors come into play for COPD. This include exposure to occupational risks, second-hand smoke and potentially also low birthweight and foetal malnutrition.

International comparison

UK COPD mortality rate ranks third in Europe. It is 1.6 times that of Germany and four times that of France. Only Hungary and Denmark have higher mortality rates than the UK among European countries.

The UK has the 12th highest age-standardised mortality rate among the 99 countries for which WHO mortality data are available. However, differences in data-recording techniques and health services make these data difficult to compare.

Figure 21: **Age standardised mortality rates for COPD by country**



Sources: WHO Detailed Mortality Database and UN GLobal population estimates for countries using full ICD-10 coding of deaths. Numbers of deaths and populations for males and females combined by 5-year age groups were averaged over available years 2001-2010 and standardised using the World Standard Population.

Cystic fibrosis

What is cystic fibrosis?

Cystic fibrosis is a life-shortening, inherited disease that affects many organs including the lungs. It causes the body to produce thick mucus, which affects the lungs and digestive and reproductive systems in particular.

One in 25 people carries a faulty cystic fibrosis gene. For someone to be born with cystic fibrosis, both parents must carry a faulty gene.

There are specific treatments used for rare gene variants, but treatment for the lung manifestations otherwise consists of physiotherapy and antibiotics.

Cystic fibrosis in the UK

Prevalence

We did not compile any prevalence or incidence data for cystic fibrosis. This is because primary care records are unreliable for providing accurate figures. However, the UK Cystic Fibrosis Registry reports that there were 10,600 people living with cystic fibrosis in 2013. Of these, 261 were newly diagnosed that year.

The number of new cases is more than double the number of annual deaths from the disease. This indicates that the number of people living with cystic fibrosis is growing, which could have a considerable future impact on health care services.

Mortality

Around 110 people – 1% of the cystic fibrosis population – die from the disease each year. This has been consistent over recent years.

Impact on hospital services

Cystic fibrosis accounts for 9,500 hospital admissions and over 100,000 hospital bed days a year. A third of these are used by children under 15.

The disease has more hospital admissions and bed days per patient than most lung diseases. We calculated that each CF patient is admitted on average once

each year, and each admission lasts on average for about 10 days. These figures are considerably greater than, for instance, those for COPD at just over 0.1 admissions and almost 1 bed day used for each patient.

Gender

Cystic fibrosis occurs equally in males and females.

Age

People are born with cystic fibrosis. In the UK, most babies are now diagnosed soon after birth by a heel prick blood test carried out when they're six days old.

Although there has been a considerable increase in life expectancy over recent years, the majority of deaths from cystic fibrosis still occur in adults aged under 65. According to UK Cystic Fibrosis Registry data, most deaths occur in the third and fourth decades of life.

Regional variation

Age-standardised mortality rates for cystic fibrosis are lower in London. This may be in part due to better specialist care in London. However, it may also be because the mutations that cause the disease occur more frequently in white Caucasians, and London is very ethnically diverse. Also, there is a greater diversity in the genetic mutations that cause cystic fibrosis in ethnically mixed populations. Some of these mutations may cause milder forms of the disease, lowering mortality rates even further.

Socio-economic analysis

We did not carry out a socio-economic analysis for cystic fibrosis.

Idiopathic pulmonary fibrosis (IPF)

What is idiopathic pulmonary fibrosis?

Idiopathic pulmonary fibrosis (IPF) is one of many types of interstitial lung disease (ILD). Interstitial means that the disease affects the interstitium, a lace-like network of tissue that supports the air sacs (alveoli) in your lungs. Idiopathic means the cause of the condition is not known. IPF is the most common type of ILD. Another, older, name for IPF is cryptogenic fibrosing alveolitis.

When you have IPF, scar tissue builds up in your lungs, making them thick and hard. This is called fibrosis. Fibrosis makes it harder for your lungs to take oxygen from the air you breathe.

The causes of IPF are not understood in detail. But it is more common if you have been exposed through your occupation to dust from wood, metal, textile or stone, or from cattle or farming. Infection with particular viruses might be another cause.

There is no cure yet for IPF, although new drug treatments have recently become available.

IPF in the UK

Note on IPF prevalence and incidence data
IPF prevalence and incidence data need to be treated with caution. This is due to:

- The range of possible codings that could be used by health care professionals to record IPF.
- The changes that have been made to the way IPF is coded. These take time to become standard practice and therefore impact on the data recorded.

To decide which codings to use, we consulted leading epidemiologists and IPF clinicians. Other interpretations of the base data may yield different results.

The primary care codes that we used to identify IPF were:

- H563.00 : Idiopathic fibrosing alveolitis
- H563.11 : Hamman-Rich syndrome
- H563.12 : Cryptogenic fibrosing alveolitis
- H563.13 : Idiopathic pulmonary fibrosis
- H563100 : Diffuse pulmonary fibrosis
- H563300 : Usual interstitial pneumonitis
- H563z00 : Idiopathic fibrosing alveolitis not otherwise specified
- H563200 : Pulmonary fibrosis

Incidence figures for 2012 have been omitted from some of the analyses. This is because changes in the diagnostic coding used to record the disease led to a significant rise in recorded incidence. It is unlikely that this reflects a real change in incidence.

With the above caveats, our clinical and epidemiological experts believe the figures presented here provide an accurate picture of IPF in the UK.

Prevalence

Around 32,500 people in the UK live with IPF. We found the prevalence rate to be about 50 per 100,000. This is more than double NICE's estimate of 15-25 per 100,000 (NICE 2015).

Our data for 2008 to 2012 indicate that prevalence may have remained steady in recent years.

Although recorded prevalence increased from 2004 to 2008, the methods and incentives for recording these data make them less reliable. They might not provide an accurate picture of actual diagnosed cases.

Incidence
IPF incidence has also remained steady. There are around 6,000 new cases diagnosed a year, which is greater than previous estimates of around 5,000 new cases a year.

The data for 2012 were excluded (see 'notes on IPF incidence and prevalence' above).

Mortality
Overall, 5,300 people die from IPF each year. This is slightly more than the previous commonly accepted estimate of 5,000.

Impact on hospital services
There are nearly 9,000 admissions a year for IPF. This is also the case for the 86,000 hospital bed days accounted for by ILDs.

Although the total impact on health services is relatively low, the impact for each person living with pulmonary fibrosis is higher than for most other lung diseases. IPF account for around 1.4% of all hospital bed days and 1.3% of all admissions due to lung disease. This is despite its having been diagnosed in less than 0.25% of people who have had a diagnosis of lung disease.

Gender
Prevalence rates suggest that IPF is 50% more common in men.

Although the gender split in mortality varied, the disease killed 60% more men than women from 2008 to 2012. In this period 13,974 men and 8,624 women died from IPF. This is broadly in line with previous estimates.

Age
The disease is more common in older age. Around 85% of diagnoses are made in people aged over 70.

Regional variation
Prevalence is highest in Northern Ireland, north-west England, Scotland and Wales. IPF is least common in London. The reasons for this are not known.

Socio-economic analysis
Incidence is not influenced by socio-economic status. This is surprising given past suggestions that IPF is linked to particular industries.

Further research is needed to confirm this and look into the reasons why.

Lung cancer

What is lung cancer?

Most lung cancers develop in the airways that carry air in and out of your lungs, but they can also start in the lung tissue itself. Primary lung cancer starts in your lung. Secondary lung cancer starts in another part of your body and spreads to affect your lung.

Over 85% of cases of primary lung cancer occur in people who smoke or who used to smoke. Breathing in other people's smoke over a long period of time can also increase your risk of getting lung cancer, as can being exposed to radon (a radioactive gas found in granite regions), and harmful dust and fumes in the workplace. Non-smokers are more likely to develop adenocarcinoma, a particular type of lung cancer.

Much progress has been made in the treatments available for people with lung cancer. Now people are usually given more than one treatment at a time, or several courses of treatment.

Lung cancer in the UK

Incidence and prevalence

Over 43,000 people are diagnosed with lung cancer each year according to cancer registration statistics. This makes it the second most common form of cancer in the UK, after breast cancer, although it kills more people. Our data suggest that incidence has been stable over the last decade. However, there have been significant variations in incidence between men and women.

Prevalence data for lung cancer are less reliable for observing trends than incidence and mortality data. This is because only half the people diagnosed with lung cancer will survive six months after diagnosis.

However, according to GP data 85,000 people living in the UK have received a lung cancer diagnosis. This includes people living with the condition, those in remission and those who have been cured.

Lung cancer prevalence rates have risen 23% since 2004. The earlier part of this trend may have been affected by changes in the way data were collated and incentivised. But prevalence still increased by 10% between 2008 and 2012. Stable incidence and rising prevalence point to improving lung cancer survival rates.

Mortality

Lung cancer kills 35,500 people a year. It is the biggest cause of death from both cancer and lung disease for men and women. It is also the fourth biggest cause of death in the UK.

The number of UK deaths from lung cancer was broadly constant for the period 2008 to 2012. Age-adjusted mortality rates declined by over a third in the last 40 years, according to Cancer Research UK data. However, this decline has slowed in recent years and there has been some fluctuation in the number of people dying from lung cancer. Deaths from lung cancer were 8% higher in 2008 than in 2004. An increase in lung cancer deaths among women during this period accounts for the majority of this overall increase. From 2008 to 2012, the decline in male mortality has been offset by the continued increase in female mortality, leading to the constant rate observed.

Impact on hospital services

Lung cancer accounts for around 45,000 hospital admissions and over 450,000 bed days a year (465,323 in 2012).

Around half of these admissions are for emergency care. Previous research indicates that up to 38% of lung cancer diagnoses are made following an emergency hospital admission. Awareness campaigns to encourage earlier presentation and diagnosis could reduce this impact on NHS services and potentially increase survival and cure rates.

Gender

Incidence rates have risen 20% in women and fallen 8% in men in the last 10 years. This reflects historical changes in smoking rates between men and women. The number of female smokers went up in the 1960s and 70s. Similarly, from 2008 to 2012 lung cancer mortality decreased by 3% for men from 19,900 to 19,300 deaths. For women, it rose by 4.5% from 15,400 to 16,100 deaths.

However, lung cancer is still more common in men than in women. As with COPD, this reflects historically higher smoking rates among men. It may also reflect men's greater exposure to harmful dust and fumes in the workplace.

Age

Lung cancer accounts for 5.9% of deaths in people aged over 64 and 8.4% of all deaths in people aged 15-64. This is in spite of the disease being rare under the age of 50.

Regional variation

Incidence rates for lung cancer are highest in Scotland, then north-east England, Wales and north-west England. This reflects the historically high rates of smoking in these regions.

Mortality rates are highest in Scotland, the north-east and north-west, followed by Wales. More research is required to find out why Wales has a higher incidence but lower mortality rate than the north-west.

Socio-economic analysis

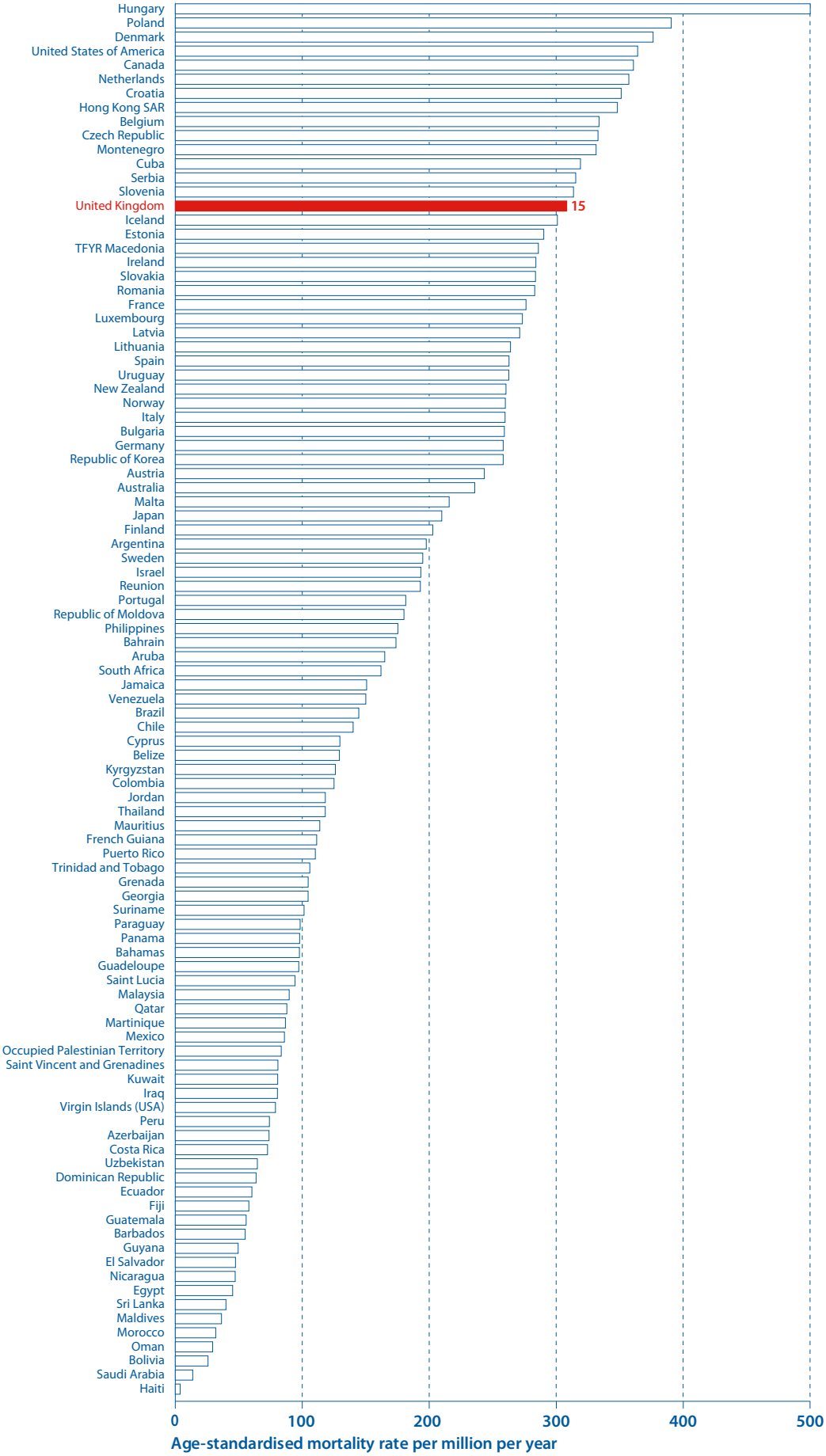
Lung cancer incidence is over 80% higher in more deprived communities. This is mostly due to higher rates of smoking. It is also likely to reflect greater occupational exposure to harmful dust, fibres and fumes.

International comparison

The age-adjusted mortality rate for lung cancer in the UK is the eleventh highest in Europe.

Among the 99 countries for which WHO mortality data are available, the UK ranks 15th. However, differences in data-recording techniques and health services make these data difficult to compare. It difficult to know how far they reflect actual rates or differences in diagnosis rates.

Figure 22: **Age-standardised mortality rates for lung cancer, by country**



Sources: WHO Detailed Mortality Database and UN GLobal population estimates for countries using full ICD-10 coding of deaths. Numbers of deaths and populations for males and females combined by 5-year age groups were averaged over available years 2001-2010 and standardised using the World Standard Population.

Mesothelioma

The disease information and research findings provided here refer only to mesothelioma of the chest, often called malignant pleural mesothelioma.

What is mesothelioma?

Mesothelioma is a type of cancer that begins to grow in the pleural membrane. This is the name for the two thin layers of cells (the pleura) that line the outside of the lung and the inside of the chest. Less commonly, mesothelioma can affect a similar lining around the abdomen or heart.

The main cause of mesothelioma is breathing in asbestos dust.

Mesothelioma is usually fatal. Treatments are currently aimed at easing symptoms and improving quality of life rather than a cure.

Mesothelioma in the UK

Prevalence

Due to the short prognosis for mesothelioma, incidence and mortality data are more reliable than prevalence data in depicting trends. However, in 2012, an estimated 5,400 people were living with mesothelioma in the UK.

Incidence

Around 2,300 people were diagnosed with mesothelioma in 2012.

Incidence rates for mesothelioma increased over the last four decades. However, they were steady during the period 2008 to 2012, suggesting that they have, as expected, begun to plateau. This reflects the tail-off in asbestos use in the 1970s, before the complete ban on asbestos products in 1999.

Mortality

In 2012, 2,431 people in the UK died of mesothelioma. This marks an increase of 13% from 2008. The Health and Safety Executive publishes mesothelioma mortality rates every year. Its data show that the annual number of deaths is now over 2,500 and is continuing to rise (HSE 2016). However, mortality, like incidence, is expected to plateau and begin to decline towards the end of the decade.

Impact on hospital services

In 2011, over 3,700 admissions and over 30,000 bed-days were due to mesothelioma.

Gender

Around 80% of mesothelioma cases occur in men. This reflects the greater likelihood of men having worked with asbestos in heavy industry or the armed forces. Five times more men than women die of mesothelioma each year.

Age

Mesothelioma is mostly diagnosed in people aged over 70. However, over 20% of diagnoses are in people aged 51–60. The disease is rare in people under the age of 50.

Regional variation

Mortality is highest in north-east England, followed by the south-east. Mortality rates are also high in certain cities, including Plymouth and Glasgow. This reflects the location of industries, like shipbuilding, in which asbestos was commonly used.

Socio-economic analysis

We found that mesothelioma prevalence increases with affluence. This is the opposite of what was expected given that asbestos was commonly used in traditionally working-class professions. The National Lung Cancer Audit 2014 Report on mesothelioma for the period 2008 to 2012 presents similar findings (NLCA 2014).

The inverse relationship with deprivation may be because the prognosis is better for more affluent groups. This could be due to earlier diagnosis, better medical care or fewer comorbid conditions. Incidence also increases with affluence, but to a lesser extent. The long lag time between exposure to asbestos and the onset of mesothelioma may also be a factor: individuals from more deprived groups at the time of exposure may no longer be in the same socio-economic group by the time of diagnosis. Further research is needed to understand this unexpected correlation.

Obstructive sleep apnoea (OSA)

What is obstructive sleep apnoea?

Obstructive sleep apnoea (OSA) is a breathing problem that happens when you sleep. It occurs as the muscles in your throat relax as you sleep, causing the throat to close. When this happens you stop breathing for a time, which is known as an apnoea. If you have severe OSA, you may experience hundreds of apnoeas a night. This can severely disrupt your sleep, which in turn can make you feel very sleepy during the day.

Lifestyle changes can help manage the symptoms of OSA, and there are effective treatments for moderate to severe OSA.

OSA in the UK

Prevalence

Around 200,000 people live with diagnosed OSA in the UK. The recorded prevalence of OSA increased by 45% between 2008 and 2012. This is unlikely to reflect a 45% increase in the number of people living with OSA. It is more likely to reflect increased recognition, more referrals and diagnostic facilities, and few people dying with the condition.

The incorrect coding of OSA is also an issue. When more general codes for heavy snoring or excessive daytime sleepiness are used instead of the code for OSA, instances of OSA remain unrecorded, leading to an underestimate of total incidence. Accurate coding is also important for targeting interventions, and identifying and treating comorbid conditions such as heart disease.

Incidence

Nearly 20,000 new OSA diagnoses are made in general practice each year. Incidence recorded in general practice remained constant during the period 2008 to 2012. However, many diagnoses are made in secondary care, for example in sleep clinics. Studies also estimate that up to 80% of cases remain undiagnosed.

Mortality

We did not compile mortality data for OSA. The disease itself is not life-threatening. However, people with untreated OSA are at greater risk of life-threatening conditions such as stroke and cardiac arrest. The risk of having a road traffic accident is also higher. Studies show that 20% of serious road accidents are caused by sleepy drivers.

Impact on hospital services

We did not compile hospital admissions and bed days data for OSA.

Gender

Over 150,000 men and fewer than 50,000 women live with a diagnosis of OSA. Incidence trends consistently show that men are two-and-a-half to three times more likely to be diagnosed with OSA. This is in line with previous research. It is partly due to men being more likely to carry weight around their neck than pre-menopausal women.

Age

Prevalence is more evenly spread across all age groups than in other respiratory diseases. However, people are most often diagnosed between the ages of 40 and 70. Prevalence is highest among people aged 50 to 70.

Regional variation

The recorded prevalence rate of OSA is highest in Scotland, the north-east and east of England. It is notably lower in Yorkshire and Humber. This regional variation may, in part, be due to regional variations in the rate of associated risk factors, especially obesity. Regional data may also be affected by variations in the awareness and approach to OSA in general practice.

Socio-economic analysis

The recorded incidence rate of OSA is consistently up to 25% higher in the most deprived quintile of society than in the least deprived quintile. This reflects the increased likelihood of people in deprived communities living with associated risk factors like obesity.

More interventions are required to reduce the prevalence of OSA and associated risk factors in deprived communities.

Pneumoconiosis and other lung diseases caused by inhaled substances

What is pneumoconiosis and other lung diseases caused by inhaled substances?

The pneumoconioses are a group of lung diseases caused by inhaling dusts.

Relatively common types of pneumoconioses include asbestosis, caused by breathing in asbestos fibres; coal worker's pneumoconiosis, caused by breathing in coal mine dust; and silicosis caused by breathing in respirable crystalline silica found in various stone rocks, sands and clays.

Breathing in dusts over the long term (such as through occupational exposure) can cause fibrosis, or scarring, of lung tissue. This results in breathing problems and severe shortness of breath.

Other lung diseases caused by inhaled substances are included in this section, such as pneumonitis, a condition that causes inflammation of the lung tissue in response to the inhalation of an external agent. One example of pneumonitis is hypersensitivity pneumonitis due to organic dust. A form of this is commonly known as "farmer's lung", mainly caused by an allergic reaction to mould spores or other agricultural products.

Note on the data
The data presented here capture a range of conditions including:

- pneumoconiosis
- hypersensitivity pneumonitis due to organic dust
- respiratory conditions due to inhalation of chemicals, gases, fumes and vapours

For completeness, the following two categories will also be mentioned as they are usually included in such analyses.

- pneumonitis due to solids and liquids
- respiratory conditions due to other external agents

However, pneumoconiosis dominates the range of codes we analysed. These included ICD10 codes J60-J70:

- J60 Coal-worker's pneumoconiosis
- J61 Pneumoconiosis due to asbestos and other mineral fibres
- J62 Pneumoconiosis due to dust containing silica
- J63 Pneumoconiosis due to other inorganic dusts
- J64 Unspecified pneumoconiosis
- J65 Pneumoconiosis associated with tuberculosis
- J66 Airway disease due to specific organic dust
- J67 Hypersensitivity pneumonitis due to organic dust
- J68 Respiratory conditions due to inhalation of chemicals, gases, fumes and vapours
- J69 Pneumonitis due to solids and liquids
- J70 Respiratory conditions due to other external agents

Data are presented here via a number of analyses:

- "Overview" – lung diseases due to external agents (J60-J70). In this analysis, data does not include conditions that may be caused by inhaled substances that are covered elsewhere in this report (such as COPD, lung cancer)
- "Occupational lung disease" (J60-J68). In this analysis, occupational 'causation' is assumed. Importantly, the definition of occupational lung disease in this chapter excludes occupation-related- asthma, COPD or cancers
- "Pneumoconioses" (J60-J65)

Pneumoconiosis and other lung diseases caused by external agents in the UK

Note
Primary care records do not provide accurate figures in this area. This is why we did not compile prevalence, incidence or socio-economic data for this condition.

Mortality

Overview

From 2008 to 2011 the number of UK deaths from lung diseases due to external agents remained steady at around 3,700 per year. However, in 2012 mortality increased to 4,200. During the period 2008-2012, the vast majority of deaths were due to "pneumonitis due to the inhalation of solids and liquids" (J69). This category is most likely not to be associated with occupational or environmental influences, and relates to inhalation of solids and liquids and subsequent medical complications. Indeed, consistently during this period, around 90% of deaths from lung diseases due to external agents were due to pneumonitis due to the inhalation of solids and liquids.

The increase in mortality that occurs from 2011 to 2012 is largely due to an increase in the number of deaths caused by pneumonitis due to the inhalation of solids and liquids and smaller increases in the number of deaths due to coal-worker's pneumoconiosis, pneumoconiosis due to asbestos and other mineral fibres.

Occupational lung disease

In 2012, 455 people died due to an occupational lung disease (asthma, COPD and occupational cancers are excluded in this definition). Annual deaths due to occupational lung disease have fluctuated over the period 2008-2012, but have increased by around 30% between 2008 and 2012.

Pneumoconioses

In 2012, 374 people died in the UK because of pneumoconioses. Annual mortality has fluctuated during the period 2008-2012, but increased by around 30% between 2008 and 2012. Notably, deaths caused by pneumoconiosis due to asbestos and other mineral fibres increased by almost 50% between 2008 and 2012 and those caused by hypersensitivity pneumonitis due to organic dust (such as farmer's lung) increased by 35% over the same period.

The reasons for these changes are not apparent from the data supplied.

Impact on hospital services

Overview

Lung diseases due to external agents accounted for around 18,000 hospital admissions and nearly 315,000 bed days in 2011. Around 95% of these admissions and bed days are due to pneumonitis caused by the inhalation of solids and liquids (J69).

Occupational lung disease

Occupational lung diseases accounted for around 800 hospital admissions and nearly 7,000 bed days in 2011. Of these, around 50% are due to hypersensitivity pneumonitis due to organic dust (such as farmer's lung) and almost 25% are due to pneumoconiosis due to asbestos and other mineral fibres.

Pneumoconioses

Pneumoconioses accounted for around 280 hospital admissions and over 3,000 bed days in 2011. Of these, around 60% are caused by pneumoconiosis due to asbestos and other mineral fibres.

Gender

Overview

The majority of deaths due to the inhalation of external agents occur in males. In 2012, 35% more men than women died because of the inhalation of external agents. A notable exception can be found in the numbers of deaths caused by pneumonitis due to the inhalation of solids and liquids (J69) which are more equally distributed in men and women – only around 10% more men died from these causes than women. This is perhaps not surprising given that these cases are likely to be unrelated to occupation.

Occupational lung disease

In 2012, over 90% of deaths due to occupational lung diseases occurred in men.

Pneumoconioses

In 2012, almost all deaths due to pneumoconioses occurred in men, with fewer than 2% in women. These patterns are likely to reflect the association between occupational lung disease and exposures in male-dominated heavy industries.

Age

Overview

In 2012, over 90% of deaths from lung diseases due to external agents occurred in people aged 65 and over. Very few deaths occur in the 0-14 age group, with five deaths occurring amongst this age group in 2012 across the full spectrum of conditions analysed. All five were caused by pneumonitis due to the inhalation of solids and liquids.

Occupational lung disease

In 2012, over 90% of deaths from occupational lung disease occurred in people aged 65 and over.

Pneumoconioses

In 2012, over 95% of deaths due to pneumoconioses occur in people aged over 65. Notably, almost all deaths caused by pneumoconiosis due to asbestos and other mineral fibres occurred in people aged 65 and over.

Regional variation

Overview

Age-standardised mortality rates for lung diseases caused by inhalation of external agents are highest in Scotland, followed by the north-east and north-west of England. These are all former centres of heavy industry.

Overall for all categories studied, hospital admission rates are high in Scotland and the north east of England, but are highest in Northern Ireland by a distinct margin. A factor might be the greater risk of developing such conditions in farming communities, and the impact of heavy industry in Belfast. More research is required to understand the reasons behind this, and also the fact that whilst hospital admission rates are high in London, mortality rates are low.

Occupational lung disease

As the vast majority of deaths due to occupational lung disease occur in men, our regional analysis of mortality rates has focused on males. In men, mortality rates for occupational lung diseases are highest in north east England, the East Midlands and Wales. This is likely to be linked to the legacy of heavy industry located in these region.

Pneumoconioses

As the vast majority of deaths due to pneumoconioses occur in men, our regional analysis of mortality rates has focused on males. In men, mortality rates for pneumoconioses are highest in north east England, the East Midlands and Wales. This is likely to be linked to heavy industry in these region.

Pneumonia and other lower respiratory tract infections (LRTIs)

What is pneumonia?

Pneumonia is an inflammation of one or both lungs, usually caused by an infection. The inflammation causes the air sacs (alveoli) inside your lungs to fill with fluid. This makes it harder for the lungs to work properly. Your body sends white blood cells to your lungs to try to fight the infection. Although this helps kill the germs, it can also make it harder for your lungs to pass oxygen into your bloodstream.

Many different kinds of bacteria, viruses and, occasionally, fungi can cause pneumonia.

Some people with mild pneumonia can manage the condition at home with antibiotics. However, some need to go to hospital. People who have been admitted to hospital with other medical problems and then develop pneumonia have a high risk of becoming very ill and may need different, more powerful antibiotics.

Many, particularly younger people, will recover from pneumonia and return to good health.

Other forms of LRTI include bronchiolitis, which commonly affects babies and children under two years old.

Pneumonia and other lower respiratory tract infections (LRTIs) in the UK

Prevalence and incidence

Around 220,000 people receive a diagnosis of pneumonia each year. Some individuals receive more than one diagnosis within a year, but for the purposes of this report, we have focused on the number of individuals who have received a diagnosis, rather than the total number of cases.

The number of people diagnosed with pneumonia has remained generally level in recent years. However, the number of cases per 100,000 was 20% higher in 2009 than other years. This may be linked to the winter of 2009-10 being the coldest in over 30 years, or it may be linked to the swine flu pandemic of the same year.

Mortality

Pneumonia is the sixth biggest cause of death in the UK. It kills 29,000 people a year and is the third biggest cause of death from lung disease. Pneumonia and LRTIs

combined kill around 30,500 a year. This is more than COPD, which is the second biggest cause of death from lung disease.

Impact on hospital services

Pneumonia accounts for more hospital admissions and bed days than any other lung disease. Over 200,000 admissions and 2.3 million bed days each year are due to the disease. The admissions rise to 325,000 and the bed days to over 3 million when we combine pneumonia with other LRTIs. LRTIs other than pneumonia have the third highest number of admissions and bed days among all lung diseases.

Gender

Pneumonia kills 40% more women than men. From 2008 to 2012, nearly 87,000 women and over 61,000 men died of the disease. Between 2004 and 2012 prevalence was also consistently higher among women. The reason for this is probably that more men die from other conditions and earlier in life. Women are more likely to live into their 80s, when most cases of pneumonia occur. In the period 2008 to 2012, nearly 12,000 men and over 8,000 women aged under 75 died from the disease. This is over 40% more men than women. However, this gender difference reverses in the over 75 age group.

Age

Pneumonia is more common in older people. Out of nearly 225,000 cases in 2012, over 32,000 (14%) were in people aged 61-70; around 38,500 (17%) were in people aged 71-80, and nearly 50,000 (over 22%) were in people aged over 80.

Older, frailer adults are less able to recover from pneumonia than younger people. Around 95% of 29,000 people who die from pneumonia are over 65 and around 87% are over 75.

However, pneumonia and acute LRTIs kill more children under 15 than any other lung disease. These diseases account for 3.5% of all deaths in this age group. In 2012, 58 under-15s died from pneumonia and 25 died from other acute LRTIs.

There were also nearly 24,000 cases of pneumonia in children from birth to age 5 and over 27,000 in children from birth to age 10. This is the most for any ten-year age group under 60.

Regional variation

In 2012, recorded incidence rates were twice as high in both north-east and north-west England than across the south of England, Wales and Northern Ireland. Conversely, relative mortality is highest in Northern Ireland, Wales, the south-east and north-west. We need more research to explain these regional variations and the mismatch between higher incidence and higher mortality. They may relate to coding practices.

Socio-economic analysis

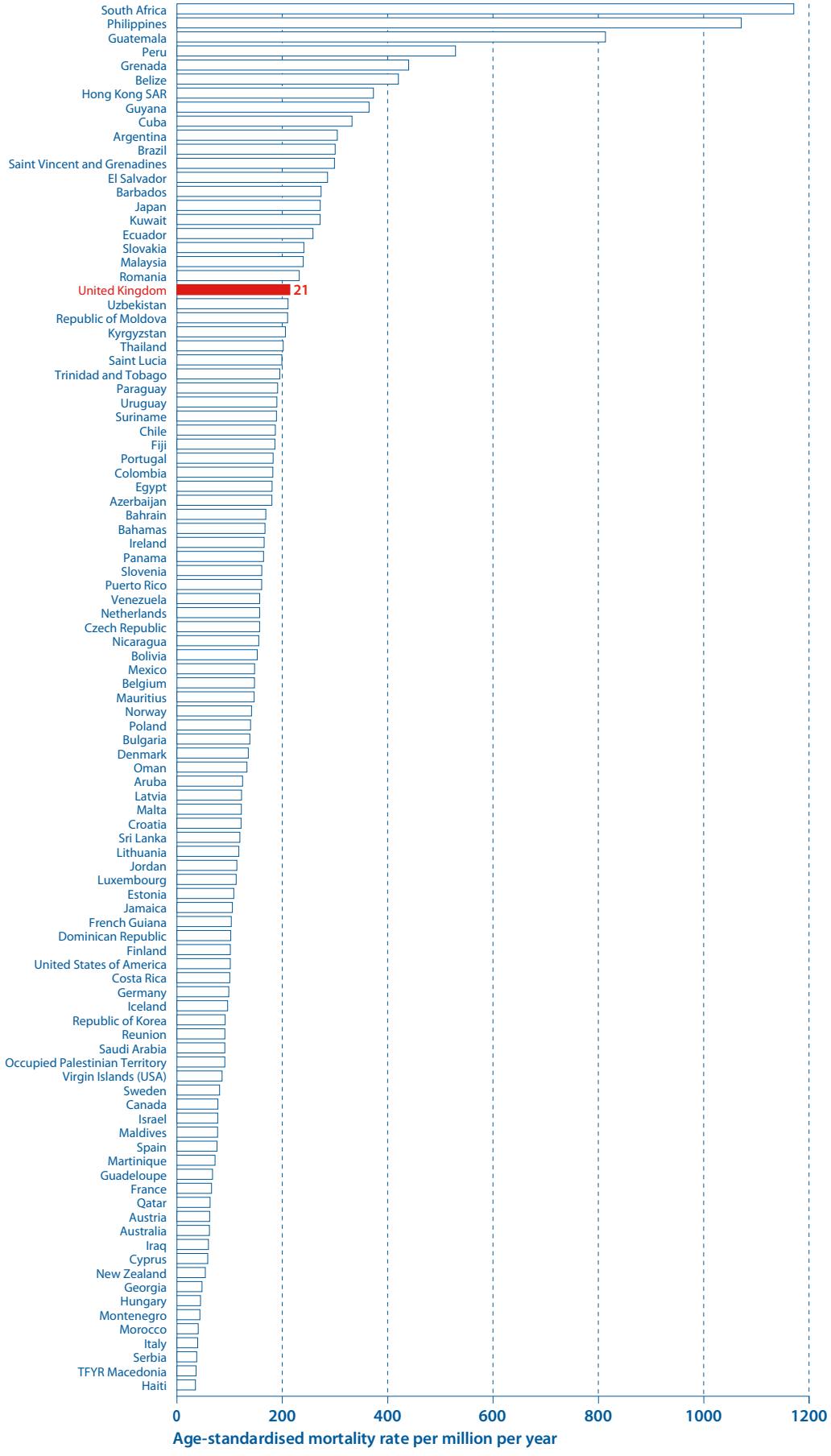
In 2012, pneumonia was around 45% more common in the most deprived quintile of society than in the least deprived. This difference has been fairly consistent over recent years. The one exception is during 2009, when incidence for the overall population was greater.

International comparison

Pneumonia mortality in the UK is the third highest in Europe. WHO data also suggest that the UK has the sixth highest number of deaths from acute LTRIs. Some of this may be due to variations in how these diseases are recorded.

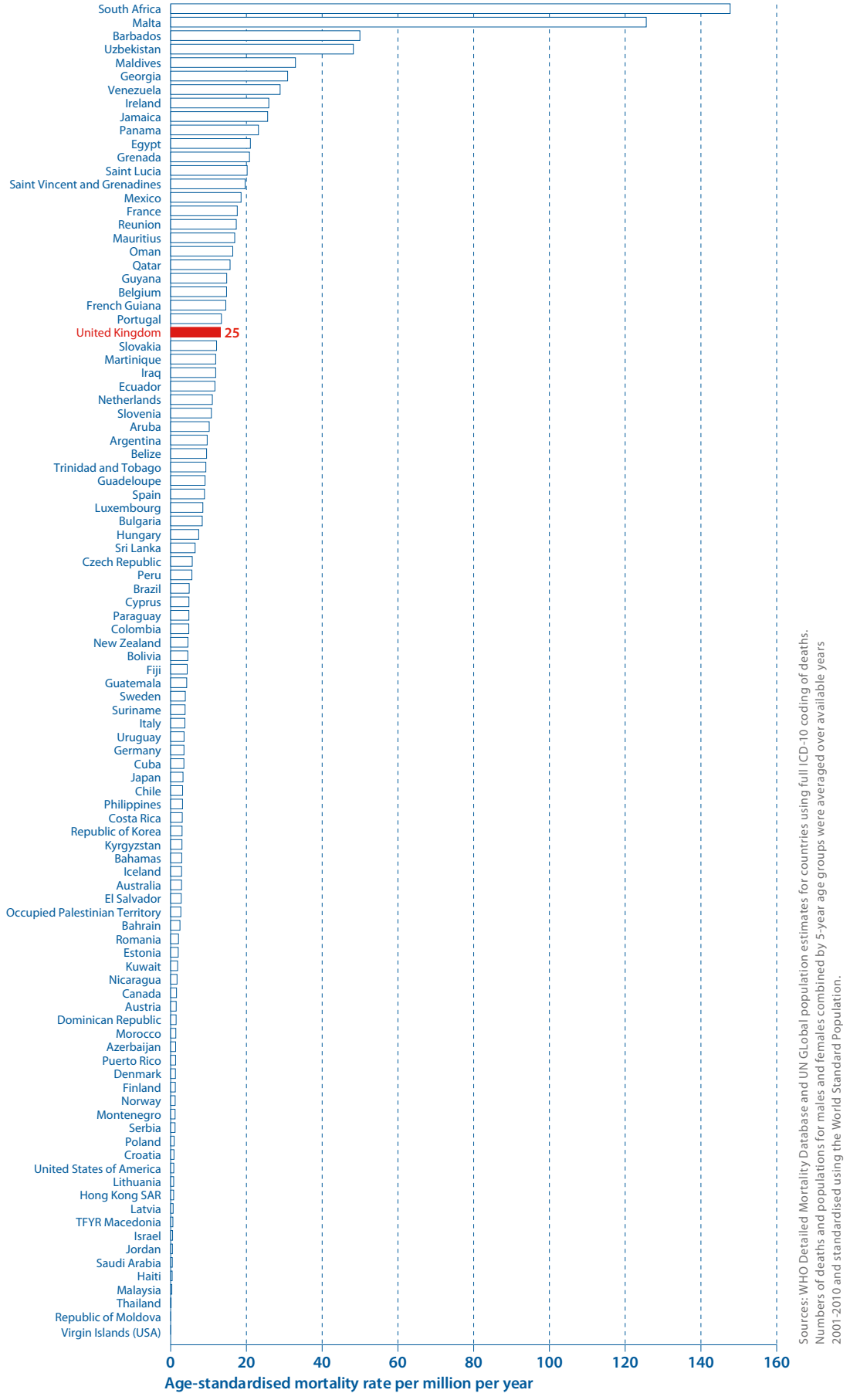
Figure 23 shows that the UK mortality rates for pneumonia rank 21st among the 99 countries for which mortality data are available. **Figure 24** shows that the UK mortality rates for LRTIs rank 25th.

Figure 23: **Age-standardised mortality rates for pneumonia by country**



Sources: WHO Detailed Mortality Database and UN GLobal population estimates for countries using full ICD-10 coding of deaths. Numbers of deaths and populations for males and females combined by 5-year age groups were averaged over available years 2001-2010 and standardised using the World Standard Population.

Figure 24: **Age-standardised mortality rates for acute lower respiratory infections**



Sources: WHO Detailed Mortality Database and UN GLobal population estimates for countries using full ICD-10 coding of deaths. Numbers of deaths and populations for males and females combined by 5-year age groups were averaged over available years 2001-2010 and standardised using the World Standard Population.

Pneumothorax

What is a pneumothorax?

A pneumothorax is often referred to as a collapsed lung. It occurs when air or gas collects in the pleural cavity, the space between your lung and your ribcage. This causes your lung to separate from the chest wall.

A primary pneumothorax occurs without a known cause, while a secondary pneumothorax occurs in someone with an existing lung disease. This condition can be a medical emergency that can cause steadily worsening oxygen levels and low blood pressure. Most cases of pneumothorax are small and resolve on their own without treatment. However, it can cause death in severe cases.

A pneumothorax can be caused by physical trauma to the chest. It can also result from a complication in medical treatment or surgery.

A small primary pneumothorax can disappear without treatment and may only need to be monitored. A larger pneumothorax, or when there are marked symptoms, may need to have the air extracted with a syringe or chest tube. Occasionally, there is a need for surgery.

Pneumothorax in the UK

Incidence and prevalence

The number of people diagnosed with pneumothorax one or more times a year has remained constant. This has been around 17 per 100,000 each year from 2004 to 2012, meaning nearly 11,000 cases in 2012. However, this contrasts with figures presented at the 2015 winter meeting of the British Thoracic Society by R. Hallifax et al. (2015). These suggest that incidence rates in the UK increased from 12.5 per 100,000 in 1999 to 13.6 per 100,000 in 2011. This would mean that, according to GP records, there were fewer than 9,000 cases of pneumothorax in 2011. More research is needed to clarify these findings.

Mortality

Death from pneumothorax is rare: in England and Wales, there were fewer than 40 deaths in 2012.

Impact on health services

Pneumothorax accounts for around 9,000 hospital admissions and 64,000 bed days a year. These figures relate to pneumothorax as a cause of admission, and do not include pneumothoraces which arise during a hospital stay, for instance as a result of surgery.

Gender

The annual prevalence of pneumothorax is twice as high in males than in females. These differences are reflected in the number of hospital admissions and bed days for each gender.

Age

The majority of pneumothoraces occur in people in their late teens and twenties (mainly primary cases), and those aged over 60 (mainly secondary cases). There are fewer cases in 0-5 year olds and 31-60 year olds. Pneumothoraces are very rare in 6-15 year olds.

Regional variation

Prevalence rates of pneumothorax are consistently highest in Scotland. They are generally low in London and on the south-east coast and inconsistent in other parts of the UK. Rates in Scotland may be due to the established link between pneumothorax and smoking. More research is needed to confirm this, and to understand the low rates in London and south-east.

Socio-economic analysis

Pneumothorax is more common in deprived groups. Higher rates of smoking in deprived communities may explain this.

Pulmonary embolism

What is a pulmonary embolism?

A pulmonary embolism happens when a blood vessel in your lungs becomes blocked. In most cases, the blockage is caused by a blood clot travelling up from one of the deep veins in your legs. This kind of clot is called deep vein thrombosis or DVT.

The cause of pulmonary embolism is often unknown. It can happen for no obvious reason. Your chance of pulmonary embolism increases when you have been inactive for a long time. This can happen on long plane journeys, or when staying in bed in hospital. Around half of all people who develop a pulmonary embolism do so while they are in hospital.

Oral contraceptives, pregnancy, being overweight and a family history of blood clots also increase the risk of pulmonary embolism

Pulmonary embolism is a serious condition because it can prevent blood from reaching your lungs. Fast medical treatment can be lifesaving.

Pulmonary embolism in the UK

Note
We did not collect prevalence or socio-economic data for pulmonary embolism. Prevalence is an inappropriate measure for an acute condition. As the condition is usually diagnosed in specialist centres, robust socio-economic data are not available on the THIN primary care database.

Incidence
Using hospital admissions as an indicator of incidence, the condition accounted for nearly 28,000 hospital admissions and 250,000 bed days in 2011. Emergency admissions for pulmonary embolism increased by 30% in the period 2008 to 2012. However, the figures we looked at do not include occurrences of the disease while already in hospital, for example after surgery, which have been estimated to account for around half of all cases. Our figures are therefore likely to be a considerable underestimate of the true incidence of pulmonary embolism.

Mortality

Between 2008 and 2012, the number of people who died from pulmonary embolism went down by 30%. There were 2,300 deaths from the condition in 2012. Patients being risk-assessed for the condition when admitted to hospital could be one reason for this. If judged to be high-risk, they are given anticoagulants to reduce blood clotting. Another factor could be the greater awareness of some of the causes of pulmonary embolism, such as sitting still for long periods on planes. Improvements to oral contraceptives may also be a factor (high-oestrogen pills increase the risk).

More research is needed to fully understand this decline in mortality from pulmonary embolism.

Gender

In 2011, 11% more women than men were admitted to hospital for pulmonary embolism. In 2011 the number of bed days for pulmonary embolism was 30% higher for women. This is expected given that pregnancy and oral contraceptives increase risk. Also, women are likely to live longer and pulmonary embolism is more common in older age due to reduced activity.

Age

Deaths from pulmonary embolism are also more common in older age. This is probably due to reduced activity. Older people are also less likely to survive a pulmonary embolism than someone who is young and fit.

Regional variation

From 2008 to 2012, age-standardised mortality for women in the East Midlands, east of England and south-west was over 20% higher than the UK average. Meanwhile, it was almost 40% lower than the UK average in Northern Ireland. For men, age-standardised mortality in the East Midlands was over 20% higher than the UK average. It was 25% lower than the UK average in Northern Ireland.

Pulmonary hypertension and other pulmonary vascular diseases (excluding pulmonary embolism)

What is pulmonary hypertension?

Pulmonary hypertension is a rare blood vessel disorder of the lung. Pressure in the pulmonary artery (the blood vessel that leads from the heart to the lungs) rises above normal levels, putting a strain on the right side of the heart, and may become life threatening.

There are several different types of pulmonary hypertension. In most people, it is associated with another condition. Severe lung disease of any sort can increase the pulmonary pressure.

There are several treatments that aim to improve the symptoms of pulmonary hypertension. The treatment you receive depends on which type of the disease you have and what is causing it.

Pulmonary hypertension and other pulmonary vascular diseases in the UK (excluding pulmonary embolism)

Note
We did not collect prevalence or socio-economic data for pulmonary hypertension and other pulmonary vascular diseases. As these are usually diagnosed in specialist centres, robust data are not available on the THIN primary care database.

Incidence
Using hospital admissions as an indicator of incidence, there were around 3,800 hospital admissions for these diseases in 2011. These increased by 25% in the period 2008 to 2012.

The data for hospital admissions in England are broken down into sub-codes. This means that figures for pulmonary hypertension can be isolated. We found that around 90% of the hospital admissions in England for these diseases between 2008 and 2012 were for pulmonary hypertension.

Mortality

There were 590 deaths from these diseases in 2012. The number of deaths increased by more than 10% between 2008 and 2012.

The mortality data for England and Wales are broken down into sub-codes. This means that figures for pulmonary hypertension can be isolated. We found that 70% of the deaths from these diseases in England and Wales were for pulmonary hypertension. This suggests that the rise in deaths from these diseases across the UK is due to a rise in deaths from pulmonary hypertension. This might be due to more awareness of the disease and therefore more people being diagnosed with it.

Impact on hospital services

There were around 3,800 hospital admissions and nearly 31,000 bed days for these diseases in 2011.

Gender

The number of hospital admissions and bed days for these diseases were both around 50% higher for women than men in 2011.

Separate data for pulmonary hypertension were not available in the WHO Hospital Morbidity Database.

Age

Deaths from pulmonary vascular diseases are more common in older age. A factor in this is likely to be that conditions that can lead to secondary pulmonary hypertension, such as COPD and bronchiectasis, are more common in older age. That conditions like COPD are more common in men would be unlikely to be significant enough to result in more cases of pulmonary hypertension in men than women overall.

Regional variation

From 2008 to 2012, age-standardised mortality for women in Northern Ireland was over 30% higher than the UK average. Meanwhile, it was over 20% lower than the UK average in Yorkshire and Humber. For men, age-standardised mortality in London was over 95% higher than the UK average. It was 30% lower than the UK average in the south-west.

We can also see this variability in emergency admissions. In the same period, for women and men, age-standardised admission in Scotland was around 60% higher than the UK average. It was 40% lower in the east of England.

More research is required to understand these complex variations.

Sarcoidosis

What is sarcoidosis?

Sarcoidosis is also known as sarcoid. It is a condition where cells in your body clump together to make small lumps called granulomas. These granulomas can develop in any part of your body, but are most commonly found in the lungs and lymph glands. When lots of granulomas develop in one area, they begin to affect how well that part of your body works, which causes symptoms.

We don't know what causes sarcoidosis, but we know it is related to abnormal behaviour of your immune system. Researchers think that sarcoidosis could be caused by something in the environment that stops your immune system working properly. Research has also shown that, for some people, the risk of getting sarcoidosis is related to their genes.

Sarcoidosis often gets better without medication and only a small number of people need treatment.

Sarcoidosis in the UK

Prevalence

The recorded prevalence rate of sarcoidosis increased by nearly 8% between 2008 and 2012. Around 108,000 people have been diagnosed with sarcoidosis in their lifetime, also known as the lifetime prevalence. According to anecdotal evidence from clinical practice, the figures for recorded lifetime prevalence are credible. However, more research would help us interrogate and understand these figures more thoroughly.

Incidence

The incidence of sarcoidosis has remained stable. Around 4,500 people were diagnosed with the disease in 2012. Annual incidence is 7 cases per 100,000. This is consistent with the range of 5 to 40 per 100,000 reported from other northern European countries. However, it is more than double the figure of 3 per 100,000 cited in the British Thoracic Society's Interstitial Lung Disease Guideline (BTS 2008). This references a paper presenting data for the 1991-1992 population.

Mortality

Around 170 people died from sarcoidosis in 2012. This is a 30% increase from 2008. The rise in mortality could be due to an increase in deaths that are certified and coded as sarcoidosis. This could be related to greater diagnostic awareness, which leads to a rise in prevalence. It could also reflect a change in preferences for death certification.

If sarcoidosis is not a common certified cause of death among those with the disease, people will die *with* rather than *from* it. Also, survival rates of people with sarcoidosis could improve if mortality from non-sarcoid causes were reduced. This would increase prevalence, and might not be reflected in the mortality statistics for sarcoidosis.

More research is needed to interrogate these relationships more thoroughly.

Impact on hospital services

Sarcoidosis caused nearly 1,300 hospital admissions and over 9,000 bed-days in UK in 2011.

Gender

Sarcoidosis diagnoses and deaths are slightly higher for women. However, there are no significant differences between men and women in incidence, prevalence and mortality.

Age

Around three quarters of people diagnosed with sarcoidosis are aged between 30 and 60. Prevalence is greatest in people aged 50 to 80.

Regional variation

The regional analysis of incidence shows that while there is considerable variation in the number of people diagnosed in each region, this was not consistent over time: regions that had higher incidence in one year frequently had average incidence the next and the reverse. Overall, there are no consistent trends that suggest incidence is higher in any particular region.

In contrast to the lack of consistent regional variation in sarcoidosis incidence, there was clear regional variation in sarcoidosis prevalence. This is because people can live for a long time after a diagnosis with sarcoidosis, meaning that very small year-on-year differences in incidence, over many years, add up to more noticeable differences in the total prevalence.

Our data show prevalence rates for sarcoidosis are consistently higher in Northern Ireland, Scotland and London. This is because certain groups, including people from Ireland and of Afro-Caribbean descent, have a genetic predisposition to sarcoidosis. There are many people of Irish descent in Scotland and Northern Ireland, and many people of Irish and Afro-Caribbean descent in London.

The diagnosis and referral practice for suspected sarcoidosis may also vary across regions, contributing to regional variations. This reflects different levels of expertise and enthusiasm in tertiary referral centres. It can also affect recorded incidence and prevalence data.

Socio-economic analysis

Sarcoidosis is 25% more prevalent in the least deprived communities than the most deprived. Incidence data for 2004 to 2012 also show that deprivation does not increase your chances of being diagnosed with sarcoidosis. This suggests that survival rates in more deprived communities are lower. More research is needed to confirm these findings and to determine the reasons for them.

Respiratory tuberculosis (TB)

What is tuberculosis?

Tuberculosis (TB) is a disease caused by a germ called Mycobacterium tuberculosis. It can affect any part of the body, commonly the lungs, and is caught from other people. The TB germs might cause one or many holes in one or both lungs.

You are most at risk of developing active TB if your immune system is damaged. You are also at high risk if your immune system works less well following an organ transplant or treatment for conditions such as cancer and rheumatoid arthritis.

TB can be completely cured if you take a course of tablets for at least six months. Most people should be treated at home only.

Tuberculosis in the UK

Incidence

There are around 4,100 recorded diagnoses of respiratory TB a year (including patients with both respiratory and non-respiratory TB). This is around the same number that the British Thoracic Society reported in *The burden of lung disease* (2006). It confirms observations that TB rates have levelled off in recent years after a period of increase from the mid-1990s.

Mortality

The number of deaths from respiratory TB each year went down by 25% from 2008 to 2012. In 2012, 282 people died from respiratory TB.

Impact on hospital services

About 2,700 hospital admissions and 44,000 inpatient bed-days in the UK each year are due to respiratory TB. This is much higher than expected given that most cases of TB should be treatable without the need for hospital admission. The reason for these high figures is in need of further investigation.

Gender

Around 60% of TB cases and deaths are in men. TB rates worldwide also show that the disease is more common in men. However, rates in the UK are also likely to be higher due to increased rates of TB among particular immigrant communities. There are slightly more men in these communities than women.

Age

Age-related data are only available for all TB cases, rather than just respiratory TB – which accounts only for around half of all TB notifications. There is therefore no age analysis in this section.

Regional variation

TB mortality is highest in London. Scotland has the next highest mortality rate, followed by the West Midlands and the East Midlands. This reflects the higher rates of TB in major urban areas like London, Birmingham and Glasgow. There is also more immigration from high-risk countries in these areas.

Scotland has the highest TB mortality rate for women.

Socio-economic analysis

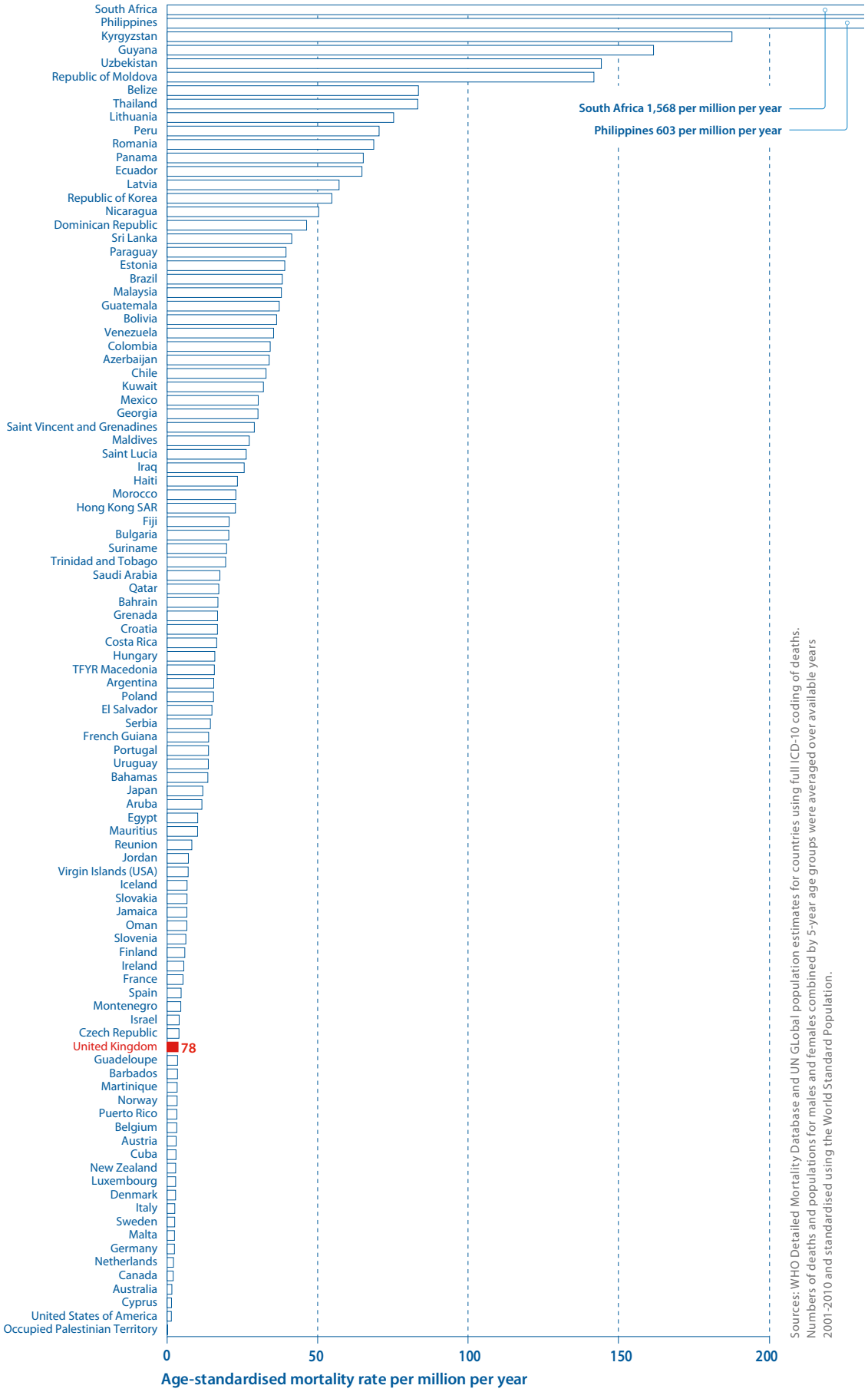
We did not compile prevalence or socio-economic data for TB. As people are put on curative treatment once diagnosed, those who have been diagnosed but cured would distort prevalence data. Also, because the condition is usually diagnosed in specialist centres, robust socio-economic data are not available on the THIN primary care database.

International comparison

The UK ranks 78th out of 99 countries included in WHO worldwide TB mortality figures. It is also 22nd of the 33 European countries included on that list. However, this does not tell the whole story given that TB mortality is higher in urban areas, particularly London. In particular, multidrug-resistant TB is more common in London, which is likely to be due in large part to immigration from Eastern Europe. According to Public Health England, the UK has the second highest mortality from TB in Western Europe. This mortality is also five times higher than in the US. The incidence of TB in some parts of east London is comparable to that in India.

71

Figure 25: **Age-standardised mortality rates for respiratory TB, by country**



Recommendations

The data presented in this report represent the most complete and up-to-date overview of lung disease in the UK currently available. And the picture they paint is a worrying one.

They show lung disease is a major factor in health inequalities, and reveal rates of some lung diseases to be far higher than was previously thought. They also show that UK lung disease mortality is among the very highest in Europe.

Overall, this report confirms that the impact lung disease has on the nation's health and health services is broadly the same as non-respiratory cancer or cardiovascular disease. Yet despite this burden, lung disease has not received a similar level of attention and investment.

Decades of prioritisation in cancer and cardiovascular disease have seen significant improvements in outcomes that have not been achieved in lung disease. For instance, our data show that the number of people dying from cardiovascular disease between 2008 and 2012 fell by 15%. The number of people dying from lung disease over the same period remained broadly stable.

If we are to make serious progress in tackling lung disease, we need levels of attention and investment to be brought into line with areas like cancer, cardiovascular disease and mental health.

Six crucial steps to achieve equal prioritisation for lung disease

1. Establish taskforces for lung health in England and Scotland, to produce new five year strategies for tackling lung disease*
2. Make respiratory one of the mandated priority areas for strategic clinical networks in England, to integrate care better and reduce lung health inequalities†
3. Establish a national respiratory intelligence network and improve data recording, collection and analysis across the UK
4. Put respiratory disease research funding on an equal footing with cancer and cardiovascular research funding
5. Update the NHS Health Check in England, and invest in awareness campaigns, evidence-based screening and greater diagnostic capacity throughout the UK
6. Invest in prevention, including tackling smoking, obesity, physical inactivity and air pollution

* Northern Ireland already has an taskforce equivalent; Wales already has a delivery plan for respiratory disease
† Similar bodies already exist in Wales, Scotland and Northern Ireland

1 Establish taskforces for lung health in England and Scotland

In 2015, independent taskforces for both cancer and mental health were established by NHS England. Tasked with producing five year strategies for delivering the vision set out in the NHS *Five year forward view*, the resultant strategies stand to transform outcomes in these two disease areas.

Already, these strategies have yielded successes. Public Health England's highly successful *Be clear on cancer* campaign had previously been shelved, but will be re-run in 2016 as recommended by the cancer strategy. £1 billion a year has been pledged to implement the recommendations of the mental health strategy.

There is no equivalent of these taskforces or strategies for respiratory disease in England or Scotland (the Regional Respiratory Forum is a taskforce equivalent in Northern Ireland, while a strategy for improving respiratory health in Wales has already been published: *Together for health – a respiratory health delivery plan*).

Taskforces for both nations should be established by NHS England and the Scottish government. Operating independently, they should include clinical and research experts, third sector representatives, Royal Colleges, professional organisations, and people living with lung disease and their carers.

The taskforces should look at improving lung health, as well as tackling lung disease. This would include prevention: tackling issues such as exercise, tobacco and air pollution. It would also include education: supporting children and young people – particularly those who have already been diagnosed with a lung condition, or who come from at risk groups – to look after their lungs.

Taskforces for lung health in England and Scotland, would ensure the whole of the UK has strategies in place to tackle the stagnation of respiratory outcomes and improve our lung health.

2 Make respiratory one of the mandated priority areas for strategic clinical networks in England

NHS England's *Review of centrally-funded improvement and leadership development* chaired by Ed Smith (the *Smith review*) outlined in 2015 that strategic clinical networks (SCNs) will continue to play a key role in the NHS in England. Although SCNs already exist for mental health, cancer and cardiovascular disease, respiratory disease has been left out of the SCN infrastructure. Given the burden of lung disease outlined in this report, a funded SCN for respiratory disease should be established in England. Equivalent bodies already exist throughout the rest of the UK (the Regional Respiratory Forum in Northern Ireland, Respiratory Health Implementation Group in Wales, and National Advisory Group for Respiratory Managed Clinical Networks in Scotland).

Informed by the work of the taskforce that we propose, and working with regional clinical senates and academic health science networks (AHSNs), the SCN would identify new models of care (as outlined in the *Five year forward view*) that could best improve respiratory outcomes in the different regions around the country.

An SCN for respiratory with a national mandate to develop regional networks, would interrogate and tackle the unwanted regional variations observed in this report. Although a number of local and regional networks already exist for this purpose (including local stakeholder networks for conditions like COPD, and specialised commissioning operational delivery networks for conditions such as IPF) there is no national mandate to support their development and impact.

Consequently, the effectiveness of these networks varies throughout the country, with stakeholder networks lacking sufficient resources, or in some areas, being entirely absent.

The outcome of such support for regional networks would, for conditions such as IPF, enable more consistent coordination between primary care and specialist services; help map and implement pathways of care between providers, and help ensure that all patients have access to a nurse specialist to help them navigate their care. For conditions like COPD, this model could better integrate stop smoking services into the treatment pathway, and address local reasons for poor uptake and completion of pulmonary rehabilitation courses.

Across all lung disease, an SCN would – as outlined by the *Smith review* – be responsible for improving local outcomes. By connecting all those involved in local health care to share best practice and innovation, they would help measure quality and outcomes, and drive improvement. This would involve clinical commissioning groups (CCGs), secondary care and specialist centres, ambulance trusts, social care, local health and wellbeing boards, and patient representatives.

Although an SCN would take investment to set up, when working with AHSNs and initiatives such as the Right Care programme, it would also improve efficiency and reduce the burden on health services, potentially leading to net savings as well as improved outcomes. Previous incarnations of regional respiratory networks have shown how this coordinated approach can do just this – for instance, renegotiated home oxygen service contracts in 2011 have been estimated to save the NHS £35 million a year.

Strategic clinical networks have been identified as a key element in delivering the vision outlined in the *Five year forward view*. As disease areas like cancer, cardiovascular disease and mental health benefit from these arrangements, it is essential that respiratory disease isn't left behind.

3 Establish a national respiratory intelligence network and improve data recording, collection and analysis across the UK

The process of compiling the data in this report, and the limitations in using the data highlighted in the introduction, flag another way in which lung disease treatment could be improved: the collection and utilisation of data.

This needs to be improved in three ways:

3.1 better collection, analysis and accessibility of data nationally, through a UK-wide national respiratory intelligence network

3.2 better sharing of data between care providers to enable better auditing and improvement of patient care

3.3 simplified, more reliable methods of data recording

3.1 Better collection, analysis and accessibility of data nationally

Effective models of nationwide data collection, analysis and accessibility have been successfully developed for other major disease areas. For instance, the Myocardial Ischaemia National Audit Project (MINAP) has provided a comprehensive database on heart attack for nearly 20 years, a period in which cardiovascular mortality has fallen considerably. The LUCADA database for cancer and its use for the annual National Lung Cancer Audit has helped drive improvements in cancer care. The National Cancer Intelligence Network, now run by Public Health England, has proven a huge success in bringing together and analysing a range of datasets from across the UK to improve our understanding of care quality and variation.

There have been positive moves to improve respiratory data collection and sharing. The National COPD Audit Programme, led by the Royal College of Physicians (RCP), has provided valuable insight into COPD care in England and Wales. Similarly, the British Thoracic Society (BTS) Lung Disease Registry Programme is driving better data collection and use for the conditions IPF and sarcoidosis.

However, such initiatives only exist for a few disease areas. The COPD audit was also limited by restrictions placed on the use GP data from England (even though access to Welsh GP data was granted). Our report presents primary and secondary care data from across the broad spectrum of lung disease in the UK, but this is the first time such a project has been undertaken since the BTS's *Burden of lung disease* report ten years ago. These data need to be presented and analysed year on year if they are to be useful in identifying and addressing variations in care and benchmarking improvements in outcomes.

Within the last five years, a National Cardiovascular Intelligence Network and a National Mental Health, Dementia and Neurology Intelligence Network have been established under Public Health England to replicate the overwhelming success of the NCIN. To bring respiratory data collection and analysis into line with these other disease areas, as our data show it needs to be, a National Respiratory Intelligence Network needs to be established. This should be UK wide or have equivalents in all four UK nations. This would improve transparency and help identify variations in treatment and outcomes that can then be addressed at a local level.

3.2 Better sharing of data between care providers to enable better auditing and improvement of patient care

Better sharing of data, particularly between primary and secondary care, is crucial in that it would enable us to follow a patient's journey from first presentation, through diagnosis to care, support and eventual outcomes. By reviewing the data collected as a whole, areas in need of improvement within this patient journey can be more easily identified and targeted.

Connecting commissioners, providers and healthcare professionals to share information and measure and benchmark outcomes is within the remit of the clinical networks, as outlined by the *Smith review*. Supported in this by local academic health science networks (AHSNs), this should include better sharing of data between primary and secondary care for the auditing of care. It could also help improve care on an individual patient basis: for instance, the introduction by regional cancer networks of formal treatment summaries (forms completed after each secondary treatment outlining considerations and

needs for a patient's subsequent primary care) have proven very successful in joining up cancer care, and could prove equally useful in respiratory care.

For wider monitoring and care assessment, NHS England's care.data programme has received criticism from health care professionals and the public. Much of this focuses on the potential sharing of data with private companies and the possibility that individual patient data could be identified. NHS England and the Health and Social Care Information Centre should work to address and overcome these concerns, as the overarching objectives are important and need to be met.

3.3 Simplified, more reliable methods of data recording

The coding used for data collection should be simplified to make collection less burdensome on health care professionals who record it, and easier to analyse to audit care. This should begin by aligning the coding used by primary care with the WHO International Classification of Diseases (ICD) coding used by secondary care. Clearer instructions need to be issued to both primary and secondary care to ensure greater consistency in how this system is used.

The UK is fortunate to have the capacity for electronic data collection and sharing and, through the NHS, an unrivalled capacity to utilise these data to improve outcomes, in one system. For the sake of the one in five people in the UK who have received a lung disease diagnosis, it is imperative that we use these advantages to improve the care they receive.

4 Put respiratory disease research funding on an equal footing with cancer and cardiovascular research funding

Despite the impact of lung disease being on a par with that of heart disease or non-respiratory cancer, this parity is not reflected in research investment.

In 2014, UK government spend on respiratory disease research was around £28 million. Twice as much (£56 million) was spent on cardiovascular disease research, and over three and a half times as much (£103 million) was spent on cancer research.

When spending by charities is taken into account, the discrepancy is even greater. Figures from the Association of Medical Research Charities show that 30% of charity medical research spend in the UK is on cancer, over 10% on cardiovascular disease, but less than 2% on respiratory disease.

Even within the funding invested in cancer research, the distribution between cancer types hugely favours non-respiratory cancers. 2014 National Cancer Research Institute figures show that investment in lung cancer research was around a third as much as investment in breast cancer, around half that invested in bowel cancer, and less than half that invested in leukaemia. This despite the fact that lung cancer kills more people each year than breast and bowel cancer and leukaemia combined.

There are well-defined respiratory research priorities not receiving the funding they need, including diagnostics, phenotyping, biomarkers, curative treatments, and effective structures for care.

This report also highlights a number of areas in need of further research. For instance, we need more research to understand the recent decline in asthma incidence; the link between asthma and social deprivation, and the differences in asthma mortality between genders and across difference areas of the UK. We also need to understand the mismatch between regional variations in prevalence and hospital admissions for COPD, and the unexpected link between conditions like bronchiectasis and IPF and higher socio-economic status.

Lung disease cannot be tackled by prevention and improved care structures alone. Bringing respiratory research investment into line with funding for cardiovascular, mental health and cancer research is crucial for finding new ways of tackling lung disease in the UK.

5 Update the NHS Health Check in England, and invest in awareness campaigns, evidence-based screening and greater diagnostic capacity throughout the UK

Early diagnosis is crucial for fighting many lung diseases, improving quality of life and outcomes, and reducing impact on hospital services.

For instance, later diagnosis with lung cancer has been shown to have a significant impact on chances of survival. Yet, research has found that over a third of lung cancer patients are only diagnosed following an emergency hospital visit, by which stage the disease is often too advanced for curative treatment. Better awareness and screening to improve early diagnosis would help improve the lung cancer figures on hospital admissions and mortality.

To this end, the decisions by Public Health England and Welsh and Scottish governments to run or continue lung cancer awareness campaigns in summer 2016 are welcome. Public Health England have also announced plans for a national campaign to raise awareness of breathlessness as a symptom of lung disease. Such campaigns that support awareness of lung conditions beyond cancer should also be run throughout the rest of the UK.

Trials of lung cancer screening in the US have also resulted in significant declines in lung cancer mortality. If European trial data expected to be published later this year show that comparable outcomes could be achieved in the UK, a screening programme should be piloted and rolled out across the UK.

The NHS Health Check includes a number of components designed to help diagnose conditions such as diabetes and heart disease. Research published this year found that this prevented around 2,500 major cardiovascular events, including stroke and heart attack, over the first five years of the Health Check.

Yet the NHS Health Check doesn't contain any components aimed at detecting lung disease. Including questions relating to breathlessness, or even simple handheld spirometry in the Health Check, would not require additional training nor significantly increase the time required to conduct each check. They would, however, help improve early diagnosis of lung disease.

Outside the Health Check, similar screening tactics could form part of standard consultation protocols, particularly where our data show high incidence of lung disease. For instance, handheld spirometry could be conducted in all GP consultations with people aged over 35 who smoke and have symptoms of lung disease (identified in NICE guidelines as risk criteria for COPD). This is being rolled out in Wales at present as part of the Respiratory Health Delivery Plan.

To improve the accuracy of diagnosis, primary care professionals need to be resourced to systematically evaluate common symptoms such as cough and breathlessness and ensure clear and timely onward referral pathways are available when these assessments suggest more complex, uncommon or rarer diseases. Links between primary care and specialist centres provided by clinical networks will support this. Health Education England, NHS Education for Scotland, and the Welsh Workforce, Education and Development Services (WEDS), should also work with professional bodies such as the BTS and Primary Care Respiratory Society UK (PCRS-UK) to ensure that all health care professionals are appropriately trained in respiratory diagnosis and care. The NHS across the UK should also look to work with organisations such as PCRS-UK and the Association of Respiratory Technology and Physiology (ARTP) to develop plans for expanding the use of spirometry and other respiratory diagnostic tools in primary care.

6 Prevention

A "radical upgrade in prevention and public health" is one of the cornerstones of the *NHS Five year forward view*. As with heart disease and cancer, there are a range of preventable factors that cause and worsen lung disease. Some, such as smoking, air pollution, obesity and lack of exercise, are shared between cancer, lung and heart disease. These factors also contribute to health inequalities, including those observed in this report.

Tackling smoking can't be considered the only way of preventing lung disease. However, smoking remains the most common cause of the two biggest lung disease killers (COPD and lung cancer), and a factor in worsening many other conditions. Tackling smoking uptake and supporting people to stop smoking should therefore form an essential part of reducing the burden of lung disease.

Considerable progress has been made in reducing smoking rates over recent years, through measures such as the bans on tobacco advertising and smoking in public places. We expect the ban on smoking in cars carrying children and the introduction of standardised packaging for tobacco products to continue this progress. However, smoking remains the single biggest cause of preventable death

in the UK. With around one in five of the UK adult population still smoking, the battle against the health impact of tobacco should in no way be considered won.

At a local level, stop smoking services need their budgets protected, and more should be invested in innovative stop smoking and awareness campaigns targeting communities with high smoking rates. Increasing the tobacco duty escalator to 5% above inflation and a levy on the tobacco industry would help fund this work, and would go some way to addressing the current shortfall between the amount of money taken in tobacco taxes and the amount smoking costs society and the UK economy.

Issuing licences to tobacco retailers that compel fuller reporting on tobacco sales would help inform local stop smoking strategies, and relieve our reliance on the tobacco industry themselves for these data. Making the sale of nicotine replacement products and e-cigarettes a condition of the licence to sell tobacco would also address the current situation in which the most harmful form of nicotine consumption – cigarettes – is also by far the most widely and readily available. Other measures, such as making exhaled carbon monoxide testing part of routine assessment in clinic consultations, during hospital stays and as part of the pregnancy pathway, should also be considered as part of the Department of Health's forthcoming tobacco strategy, and other national tobacco strategies across the UK. Health professionals should want to and feel confident to treat tobacco dependency as part of any care plan.

To help reduce the impact air pollution has on the UK's lung health requires urgent cross-departmental government action. A range of measures could be adopted as part of a comprehensive government air quality strategy.

For instance, the UK vehicle tax system should be revised to remove incentives to buy and use diesel vehicles, which contribute the majority of harmful particulate and nitrogen dioxide pollution in urban areas. Clean air zones, in which safe active travel (cycling and walking) is encouraged, would reduce local pollution rates and help encourage a more physically active population. Improved monitoring and planning would help reduce the exposure of at-risk groups, such as children and people affected by lung disease. Independent, real-world vehicle emissions testing would provide more accurate information on the levels of emissions. Further policy recommendations for tackling air pollution are outlined on the BLF website.

As highlighted in the RCP report *Every breath we take*, indoor air pollution also presents a risk to lung health. Second-hand smoke can have a considerable impact on lung health, especially in children exposed to smoke. Beyond stop smoking support, campaigns such as the Scottish government's *Take it right outside* campaign can help reduce the impact of second-hand smoke indoors. Similar campaigns should be considered throughout the rest of the UK. Other sources of indoor air pollution include indoor gas appliances, such as gas cookers. More research is needed to fully understand the impact of indoor air pollution on lung health in the UK.

When considering prevention of lung disease, it is also important to look at the full life course. This includes looking at the reasons behind the social patterning of exposures to the causes of lung disease – the causes of the causes. Even *in utero*, factors such as poor nutrition and smoking during pregnancy can have a considerable impact on the long-term respiratory health of an individual.

Our vision is that everyone can breathe clean air with healthy lungs. This requires both prevention and better treatment and care for lung disease, from the earliest to the end stages of life. We hope policy-makers across the UK will join us in this 'battle for breath'.

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